WORLD FEDERATION OF HEMOPHILIA

REPORT ON THE

ANNUAL GLOBAL SURVEY 2019

WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

October 2020

Report on the Annual Global Survey 2019 is published by the World Federation of Hemophilia.

All data are provisional.

World Federation of Hemophilia
1425, boul. René-Lévesque Ouest, bureau 1200
Montréal, Québec H3G 1T7
Canada
Tel. (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
Website: www.wfh.org

TABLE OF CONTENTS

INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2019

The Report on the Annual Global Survey (AGS) 2019 shows an international snapshot of hemophilia patient identification and access to care. This report includes selected demographic and treatment data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. Over the years this report has given the national member organizations (NMOs) affiliated with World Federation of Hemophilia (WFH), healthcare providers and policy makers an overview of the patterns and trends in hemophilia and its treatment. The annual report offers useful information to support efforts in improving or sustaining the care of people with bleeding disorders, and to assist with advocacy and program planning. The WFH strives for continuous improvement every year and is appreciative of all the effort and support put forth by the NMOs.

Supplementary charts and graphs using 2019 data can be found on the website at: **https://www.wfh.org/en/our-work-research-data/annual-global-survey**.

Methodology

In 1998, the WFH began collecting information on hemophilia care throughout the world. This survey, called the WFH AGS, collects basic demographic information, data on access to care and treatment products, and information on the prevalence (the percentage of the population affected) of infectious complications such as human immunodeficiency virus (HIV) and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to NMOs linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization.

Annual Global Survey 2019

In March 2020, as data collection for the Annual Global Survey 2019 started, the coronavirus disease 2019 (COVID-19) was declared a pandemic. As the world at large navigated through shutdowns during this difficult time, the same was true for our dedicated bleeding disorders community, Hemophilia Treatment Centres (HTCs) and NMOs. Although most of the countries were able to provide the WFH with their 2019 country data, this was not the case for all, and this missing data is evident in some of the figures in the 2019 report. Despite the many challenges faced, as a result of this pandemic, the Report on the AGS 2019 does manage to include data on more than 320,000 PWH, VWD and other bleeding disorders in 115 countries. A list of participating countries and the last year they provided data can be found on page 32.

Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed. The survey questionnaire is included at the end of this report. Total population numbers are used in population statistics and in the calculation for factor VIII and IX per capita. The source from 1999 to 2014 was The World Factbook, Central Intelligence Agency. As of 2015, this was changed to The World Bank Group. The regional classification used in the AGS is based on the WHO regional classification.[1]

Comments on data collection

Participation in the AGS is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. Some countries are only able to provide detailed data on gender, age, inhibitors and HIV/HCV infection for a limited subset of patients. For example, they may know the total number of PWH in the country but only have age and sex data from a single treatment centre. This report provides information on the annual usage of treatment products for 2019 only. It includes only those countries where the NMO provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2019.

Some countries are not reporting for the whole country and in some cases the numbers reported may be based on an estimate or from one region or certain treatment centres only. The amounts reported may only be factor bought through government and not through other sources. Not all NMOs are able to report on all products used in their country. Although factor use per capita is a useful way to compare the availability of treatment products between countries, it is not a reflection of how individual patients are treated. For example, in a country with a lower than expected number of identified patients, the amount of treatment product available per patient is higher than the per capita number would suggest.

Comments on the graphs

The graphs showing the increase over time in patients identified (Figures A1 and A2) contain historical data from the AGS. These graphs were created using aggregate numbers to demonstrate the increase in patients identified over time. If a country did not report the number of identified patients in 2019, data from the latest year they reported is used, on the assumption that the number of patients did not change substantially from one year to the next. For all other tables and graphs, the analysis was done using only data from countries that responded in 2019, with the number of respondents as the denominator.

Calculating prevalence and prevalence at birth of hemophilia

In 2003, the World Federation of Hemophilia estimated that 400,000 patients with hemophilia were expected globally. This figure came from then-current estimate of the prevalence of hemophilia (e.g., 13.4 per 100,000 males and global population of 6 billion), based on US CDC data,[2] and did not distinguish severe from mild patients.

Over the subsequent years, three main findings became available:

a) The large variability of hemophilia incidence and prevalence across countries was measured and the impact of socio-economic status was highlighted[3,4]
b) Many large studies focusing on inhibitor development provided new data on previously untreated patients (PUPs) and prevalence at birth of hemophilia[5]
c) The importance of distinguishing a) the number of mild and severe hemophilia patients and b) the difference between prevalence at birth and prevalence over the whole population as indexes of maturity of the health care system.[6]

New data on prevalence at birth (incidence) and prevalence has been recently estimated, separately for severe and all patients.[7] The prevalence at birth was estimated from the FranceCoag data, and confirmed with data from the United Kingdom and Canadian registries. Specifically, the number of patients by year of birth was retrospectively assessed and analyzed over many years. This novel approach estimates the prevalence at birth of hemophilia patients:

24.6/100,000 males for ALL hemophilia A	9.5/100,000 males for severe hemophilia A
5.0/100,000 males for ALL hemophilia B	1.5/100,000 males for severe hemophilia B

Using these new estimates for prevalence at birth and the current live birth population globally from UNICEF (at least 130 million babies are born each year) approximately 20,000 people with hemophilia to be born worldwide each year, of which about 7,000 are severe.

Unfortunately, the mortality rate for people with hemophilia is higher than the mortality rate in the general population due to inadequate care over a patient's lifetime (e.g., limited to no treatment, HIV/AIDS, HBV, and HCV). As a result, we estimated the prevalence of hemophilia using registry data from Australia, Canada, France, Italy, New Zealand, and the United Kingdom:

17.1/100,000 males for ALL hemophilia A	6.0/100,000 males for severe hemophilia A
3.8/100,000 males for ALL hemophilia B	1.1/100,000 males for severe hemophilia B

Using these estimates and the current world male population of 7.5 billion (3.8 billion males), the expected number of patients with hemophilia worldwide is 794,000, of which about 270,000 are severe.

In this report, the prevalence rate is used to calculate the expected number of patients per region (Figure A3). This number is sequentially compared to the identified number of patients reported in this survey to illustrate the progress in patient outreach, identification, and diagnostic capabilities globally and to identify areas for improvement.

Please consider the following caveats about the data in this report:

a) Founder effects can create pockets of patients concentrated geographically. The founder effect occurs when a small population grows in isolation and there is little genetic dilution. This can increase the local frequency of genetic disease compared to the general population. This may occur with hemophilia and all the rare bleeding disorders. In the extremely rare bleeding disorders, consanguinity may lead to an increased incidence in some countries.

b) Countries with small populations can appear to have too many identified patients. Countries submitting data to the WFH range in population from 287,025 to over a billion. With a small denominator (total population), just a few extra identified patients (the numerator) can create the appearance of huge percentage differences between expected and identified patients when really there are only a few more patients than expected.

c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they do not require treatment. In countries with different health care systems, it is likely that patients who do not require treatment will not be identified.

d) Definitions may vary from country to country. Countries may use different definitions to diagnose mild hemophilia and other disorders. In the case of rare bleeding disorders, some countries may report heterozygous patients while other countries report only patients with bleeding symptoms.

e) Some countries are reporting every patient who seeks treatment while other countries are using methods such as laboratory screening or follow up with family members to identify additional patients who do not require treatment.

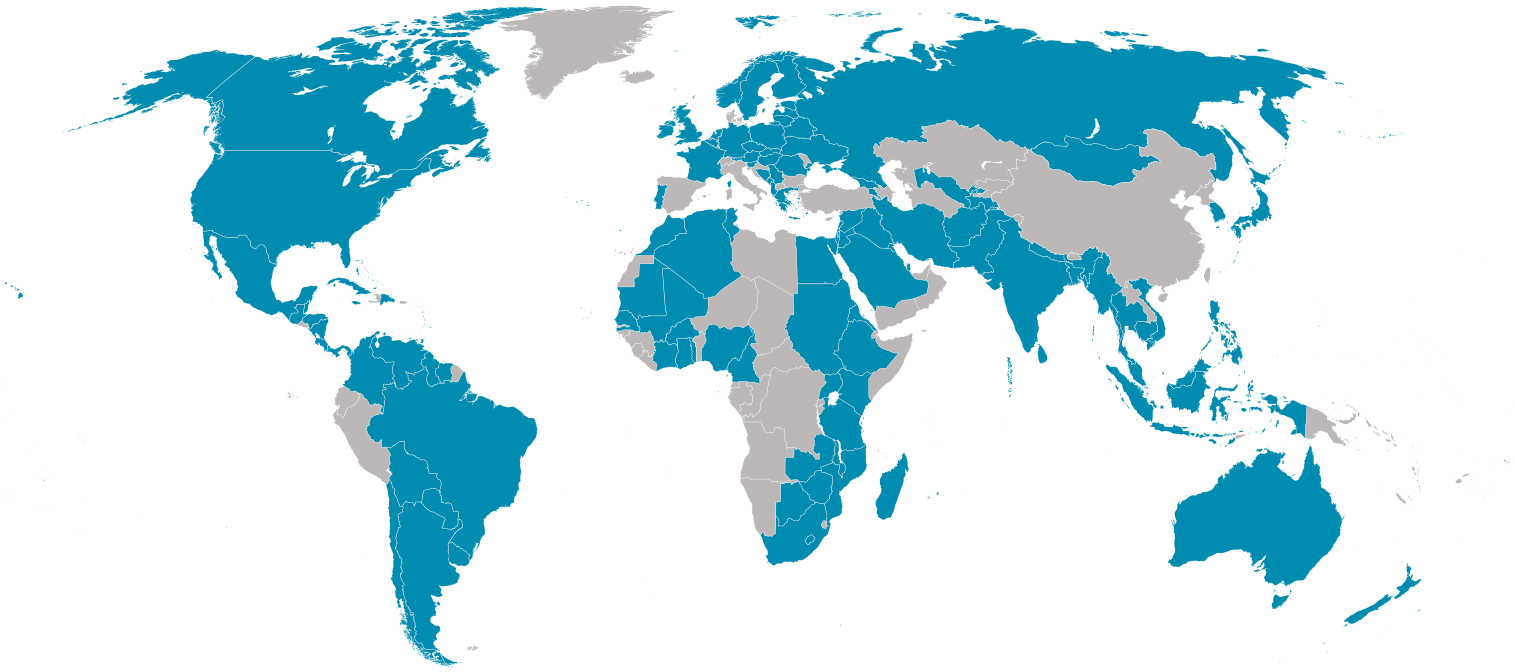
f) Methods of data collection and the state of registries can vary. Maintaining accurate registries can be time consuming and expensive. It is possible that some registries contain patients who have been double-entered or have died. Even wealthy countries with excellent registries have to carefully review their records to avoid over-counting. Countries with large populations are more susceptible to over-counting and it can be harder to keep track of births and deaths. Some patients may be registered in more than one treatment centre and validation of registry data is more difficult.

g) There is also the possibility that the death rate due to HIV and HCV is not the same around the world. In some countries infection rates may be lower, while other countries may have had better treatment for infected people with hemophilia.

The Report on the AGS is collected under the supervision of the WFH Data & Demographics Committee, including:

COUNTRY REPRESENTATION

Annual Global Survey 2019



Countries included Countries not included

The WFH has a total of 140 national member organizations (NMOs). The Report on the Annual Global Survey 2019 includes data from 115 NMOs.

ANNUAL GLOBAL SURVEY 2019

KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY (2019)

NUMBER OF COUNTRIES
in this survey

115

RESPONSE RATE
from WFH National Member Organizations

82%
(115/140)

NUMBER OF IDENTIFIED PATIENTS

324,648

People with hemophilia..... **195,263**
Hemophilia A..... **157,517**
Hemophilia B..... **31,997**
Hemophilia type unknown **5,749**
von Willebrand disease **80,302**
Other bleeding disorders..... **49,083**

FACTOR VIII USAGE PER CAPITA

1.058 IU

(0.174 – 4.312) Median (IQR)

(101 countries, 72% of world population)

FACTOR

FACTOR IX USAGE PER CAPITA

0.155 IU

(0.017 – 0.673) Median (IQR)

(93 countries, 66% of the world population)

REPORT ON THE ANNUAL GLOBAL SURVEY 2019 SUMMARY DEMOGRAPHICS

TABLE 1. **Demographics**

	2019 Total
Number of countries in this survey	**115**
World population covered by countries in this survey report	**5,537,527,603**
Total number of people with bleeding disorders identified	**324,648**
Number of people identified with hemophilia	**195,263**
Number of people with hemophilia A	**157,517**
Number of people with hemophilia B	**31,997**
Number of people with hemophilia type unknown or type not reported	**5,749**
Number of people identified with VWD	**80,302**
Number of people identified with other bleeding disorders	**49,083**
Number of hemophilia A patients with clinically identified inhibitors	**6,306**
Number of hemophilia B patients with clinically identified inhibitors	**330**

FACTOR USAGE SUMMARY

TABLE 2. **Factor VIII usage 2019**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor VIII usage	**2.595 IU (3.139)**	**101**
Median global per capita factor VIII usage	**1.058 IU**	**101**
Interquartile range (IQR) global per capita factor VIII usage	**4.138 IU (0.174 to 4.312)**	**101**
Total consumption of factor VIII concentrates	**9,998,003,157 IU**	**101**

TABLE 3. **Factor IX usage 2019**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor IX usage	**0.428 IU (0.612)**	**93**
Median global per capita factor IX usage	**0.155 IU**	**93**
Interquartile range (IQR) global per capita factor IX usage	**0.656 IU (0.017 to 0.673)**	**93**
Total consumption of factor IX concentrates	**1,515,896,366 IU**	**93**

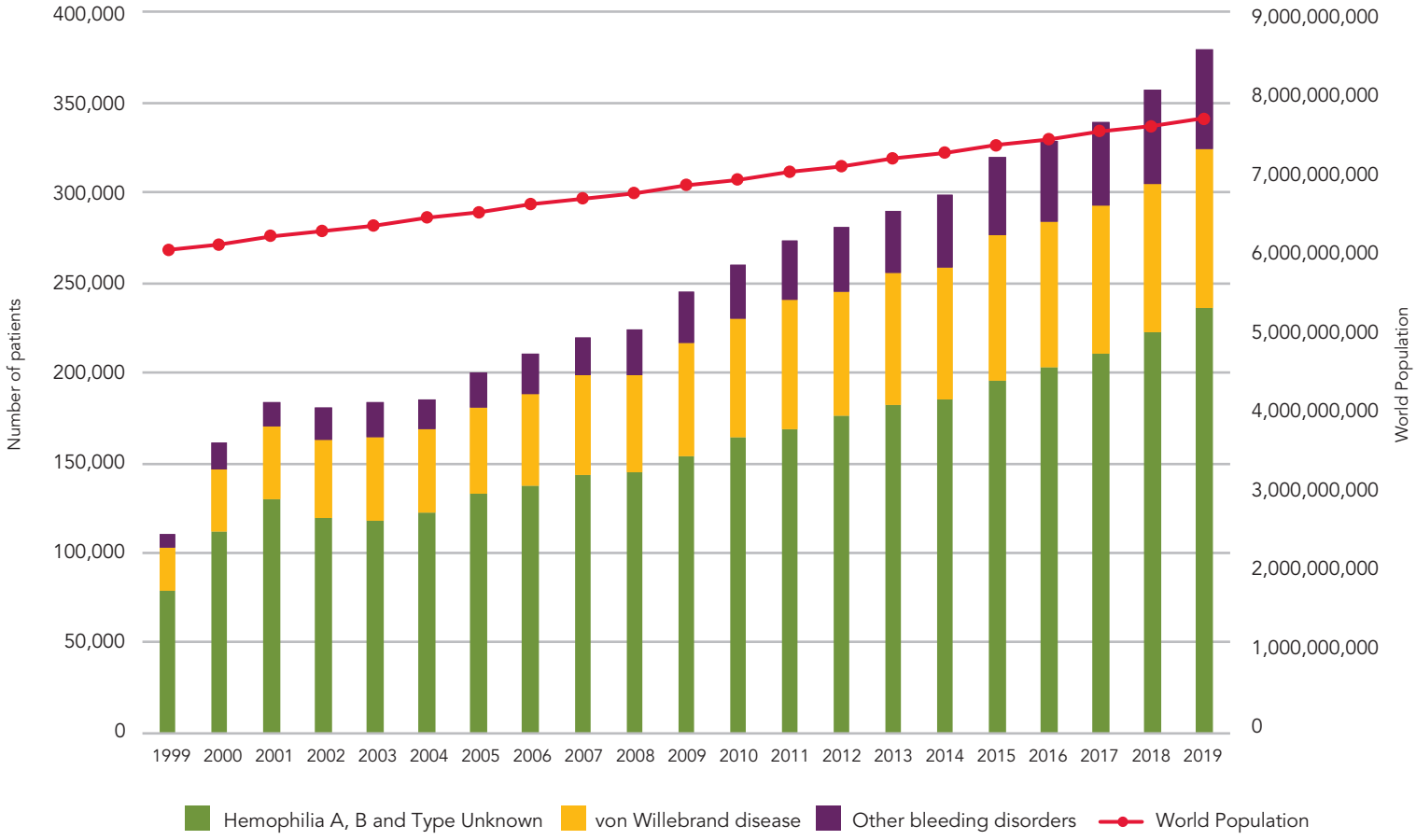
The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using very little factor, reports one year and not the next, then this will have a significant effect on the mean and median from year to year. The standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

TABLE 4. **Factor use in 2018 and 2019**

	2018	2019	NUMBER OF COUNTRIES REPORTING
FACTOR VIII			
Mean (SD) global per capita factor VIII usage	2.498 IU (3.209)	2.595 IU (3.164)	98
Median global per capita factor VIII usage	0.934 IU	1.052 IU	98
Interquartile range (IQR) global per capita factor VIII usage	3.717 IU (0.121 to 3.839)	4.147 IU (0.164 to 4.311)	98
FACTOR IX			
Mean (SD) global per capita factor IX usage	0.386 IU (0.537)	0.426 IU (0.613)	91
Median global per capita factor IX usage	0.119 IU	0.155 IU	91
Interquartile range (IQR) global per capita factor IX usage	0.608 IU (0.014 to 0.623)	0.651 IU (0.671 to 0.019)	91

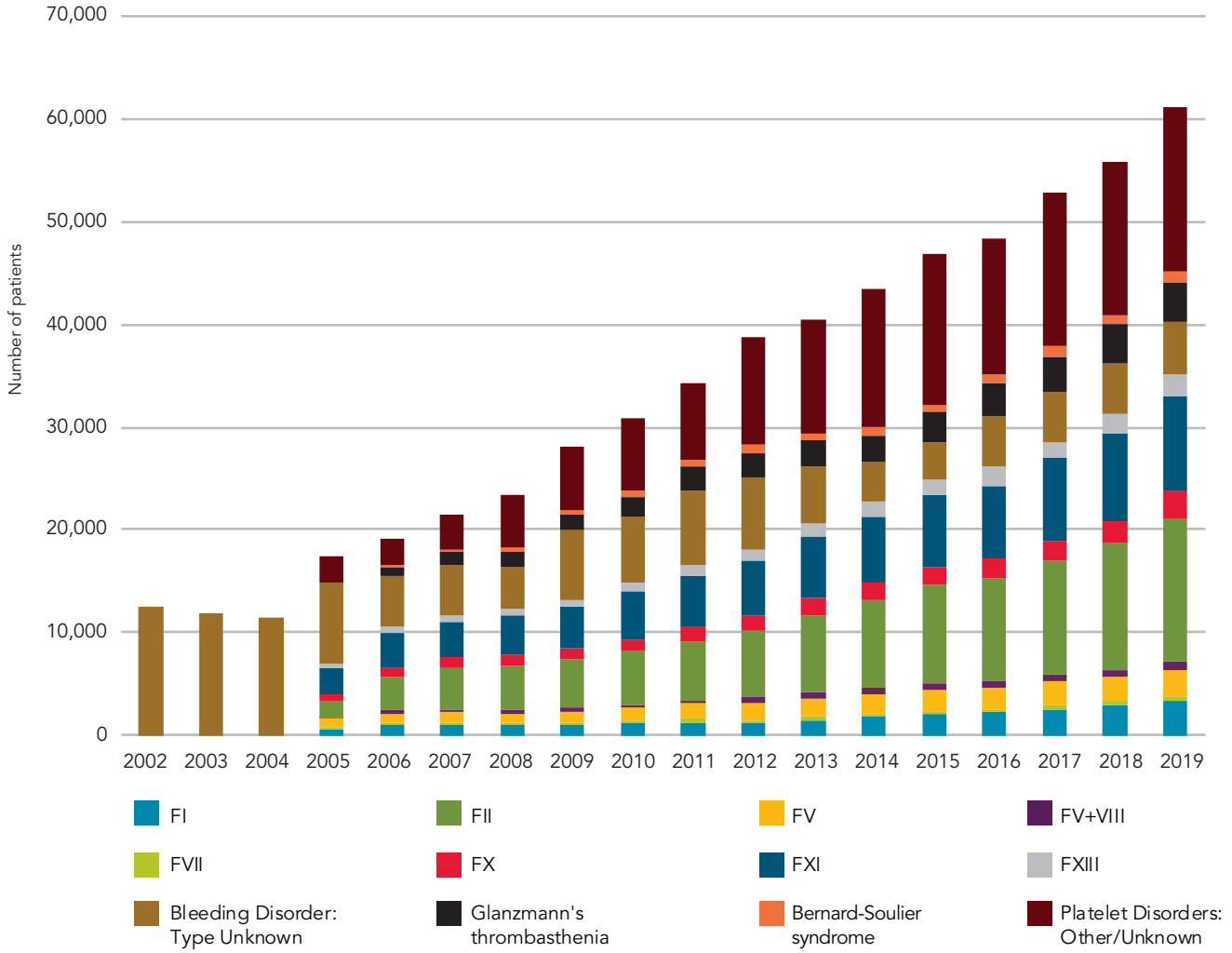
This table show the mean, median and interquartile range (IQR) of per capita factor usage for the countries that reported in both years indicated. The standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

FIGURE A1. **Identified patients over time – all bleeding disorders**



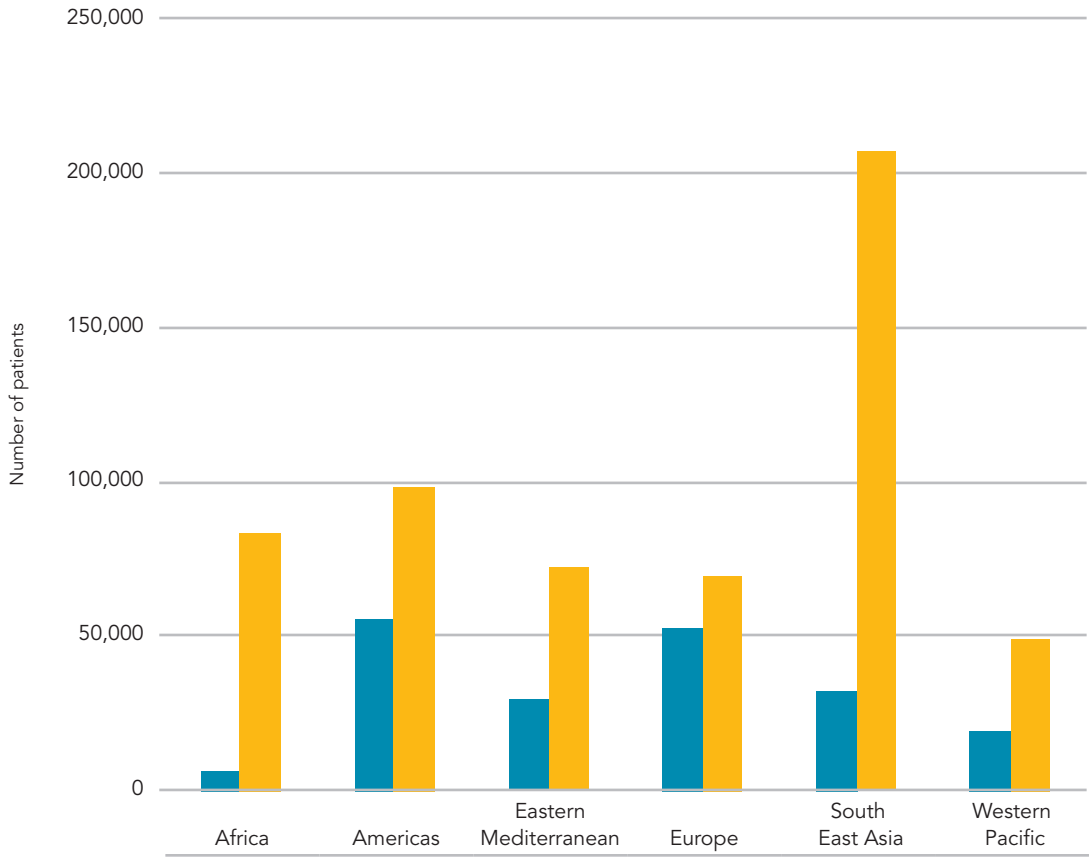
This graph was created using aggregate numbers to demonstrate the increase in patients identified over time. This graph contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next.

FIGURE A2. **Identified patients over time – other rare bleeding disorders**



This graph was created using aggregate numbers to demonstrate the increase in patients identified over time. This graph contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next.

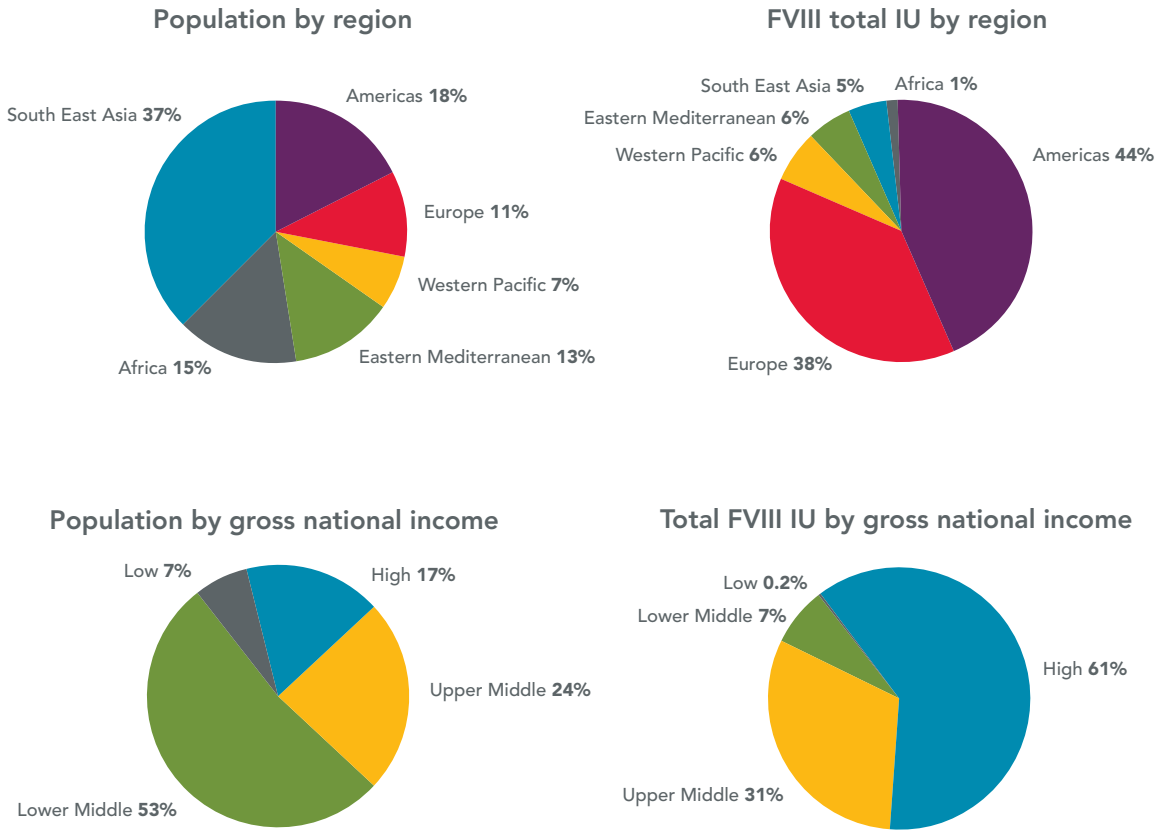
FIGURE A3. **Number of identified vs. expected hemophilia patients**



	Africa	Americas	Eastern Mediterranean	Europe	South East Asia	Western Pacific
Identified number of patients	6,387	55,317	29,117	52,354	32,735	19,353
Expected number of patients	83,725	98,727	72,584	69,690	207,344	49,371
Percent of identified patients	**8%**	**56%**	**40%**	**75%**	**16%**	**39%**

This graph was created by calculating expected number of patients using the prevalence of 21 per 100,000 males in hemophilia.[7]

FIGURE B. **Global distribution of factor VIII use**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

FIGURE C1. **Country representation by region**

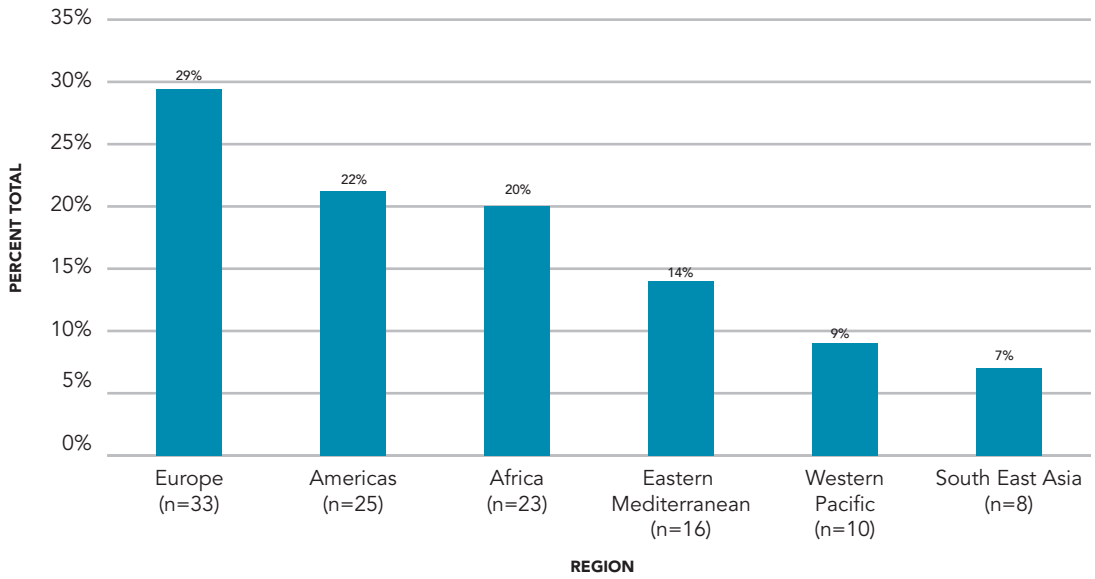
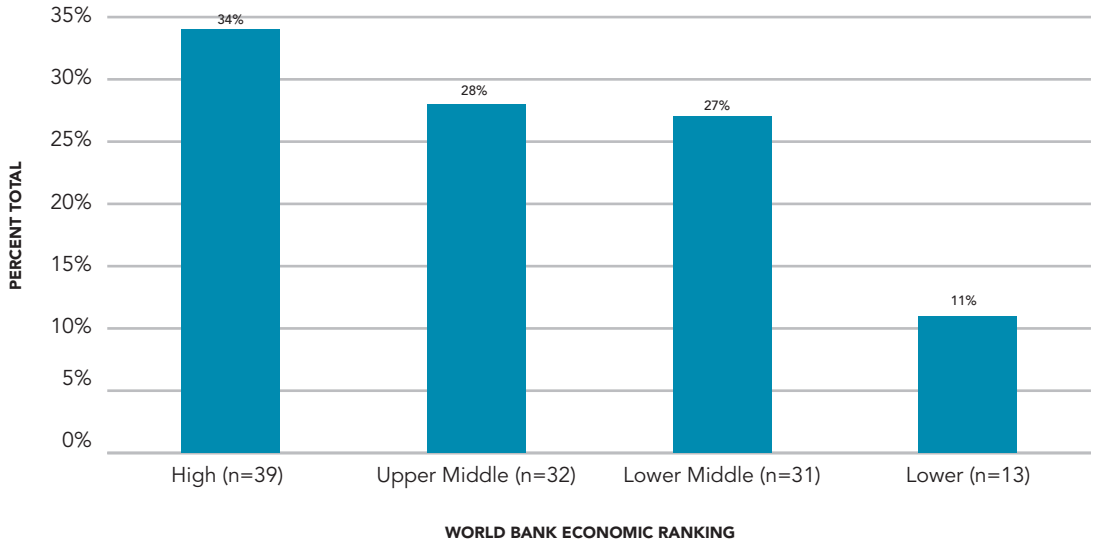


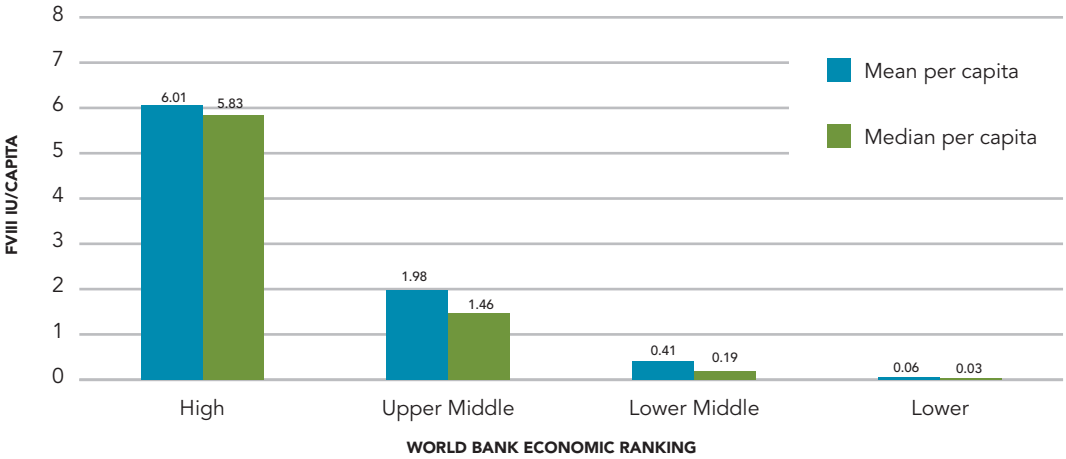
FIGURE C2. **Country representation by gross national income**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

FIGURE D. **Mean and median global factor VIII per capita 2019**

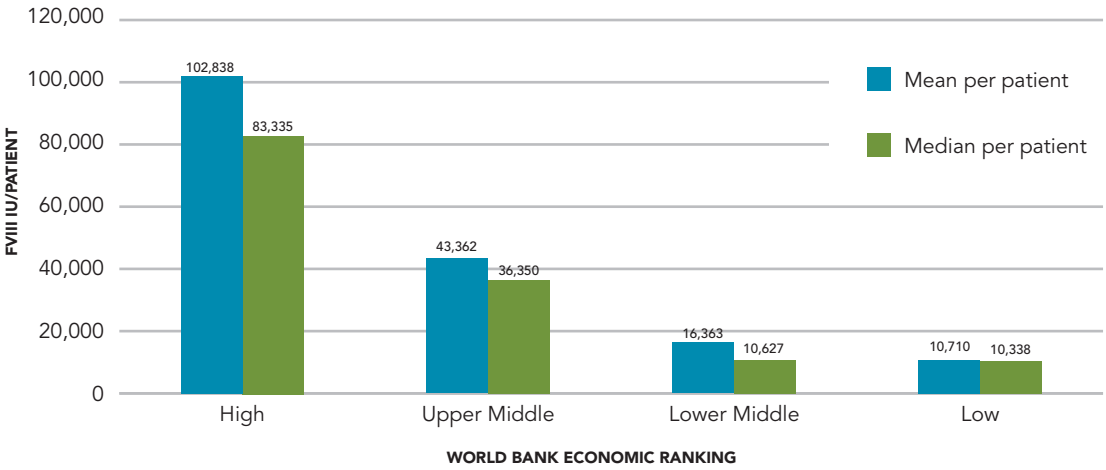
(Data from 101 countries.)



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

FIGURE E. **Mean and median global factor FVIII per patient 2019**

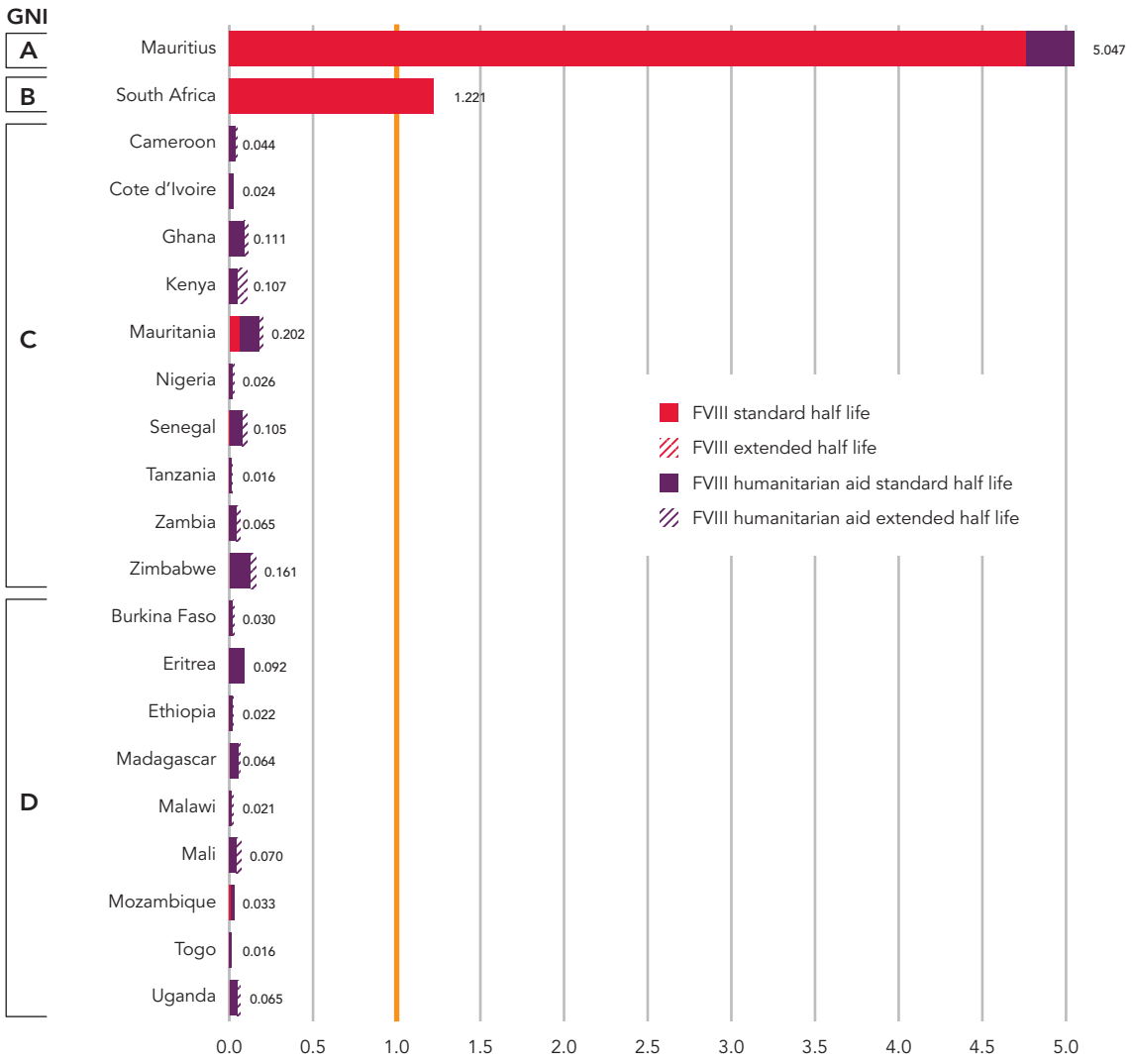
(Data from 101 countries.)



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

Numbers in Figure E are calculated based on reported factor VIII use and the number of identified hemophilia A patients. We do not have data on individual treatment. WFH humanitarian aid donations are included.

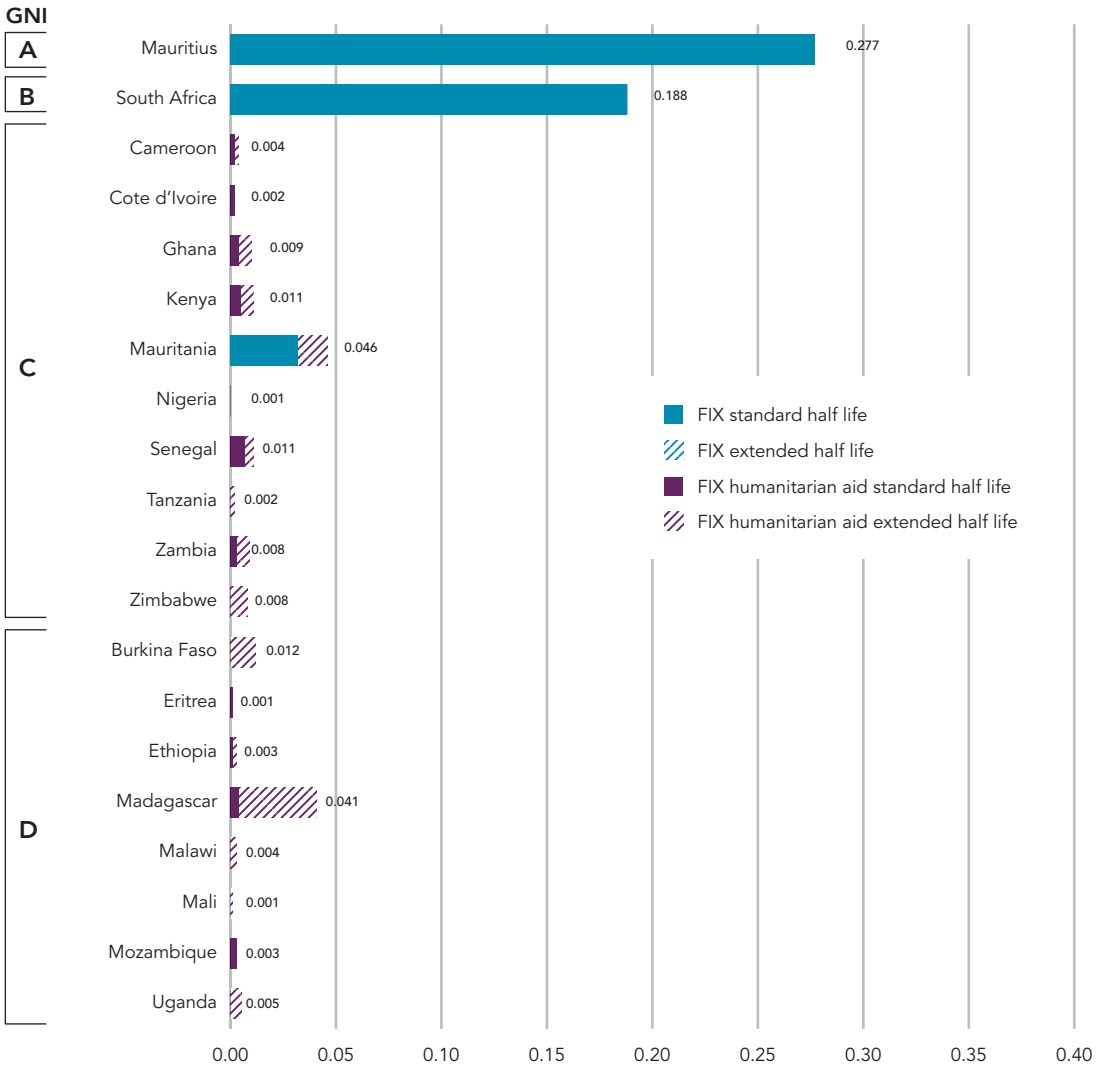
FIGURE F1a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

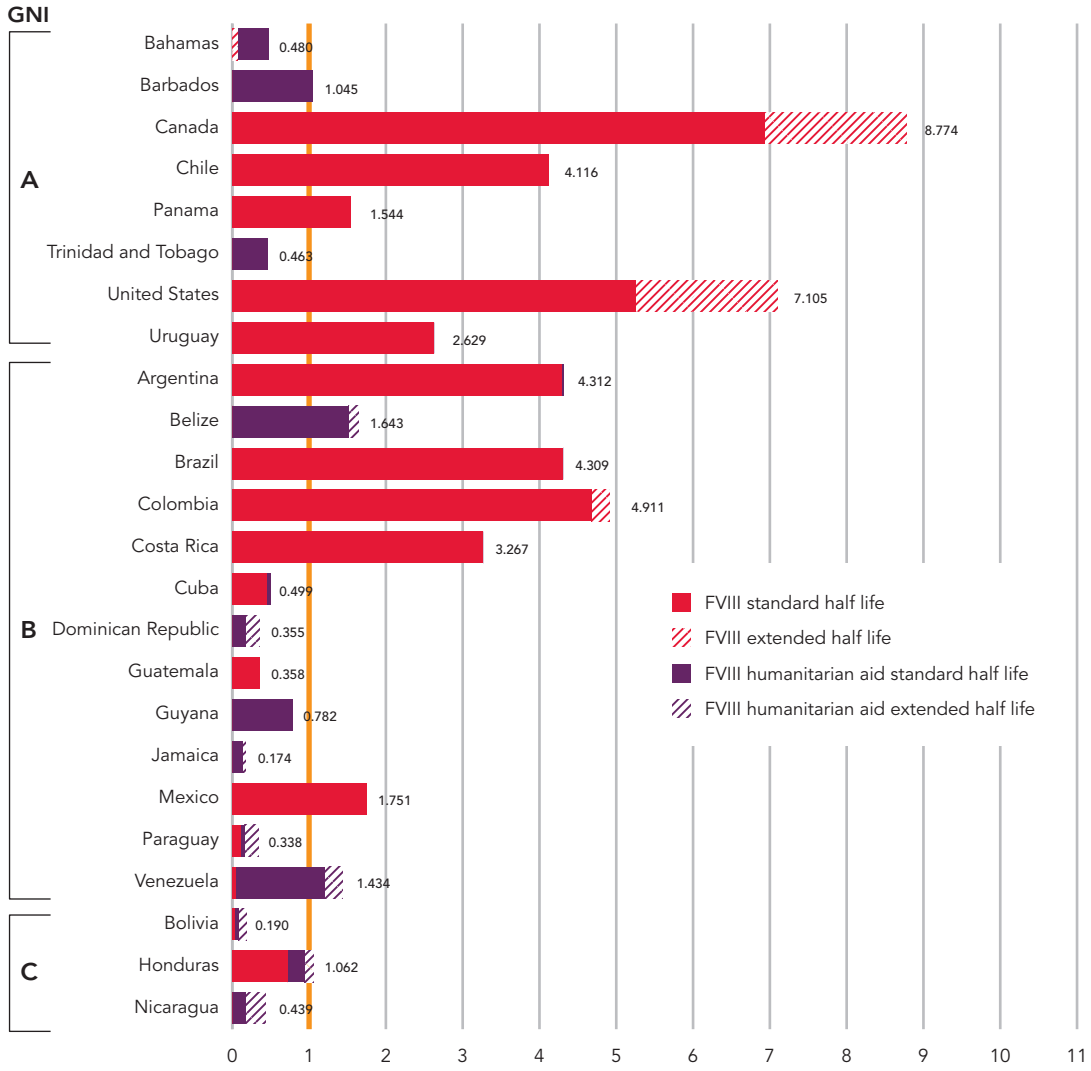
FIGURE F1b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

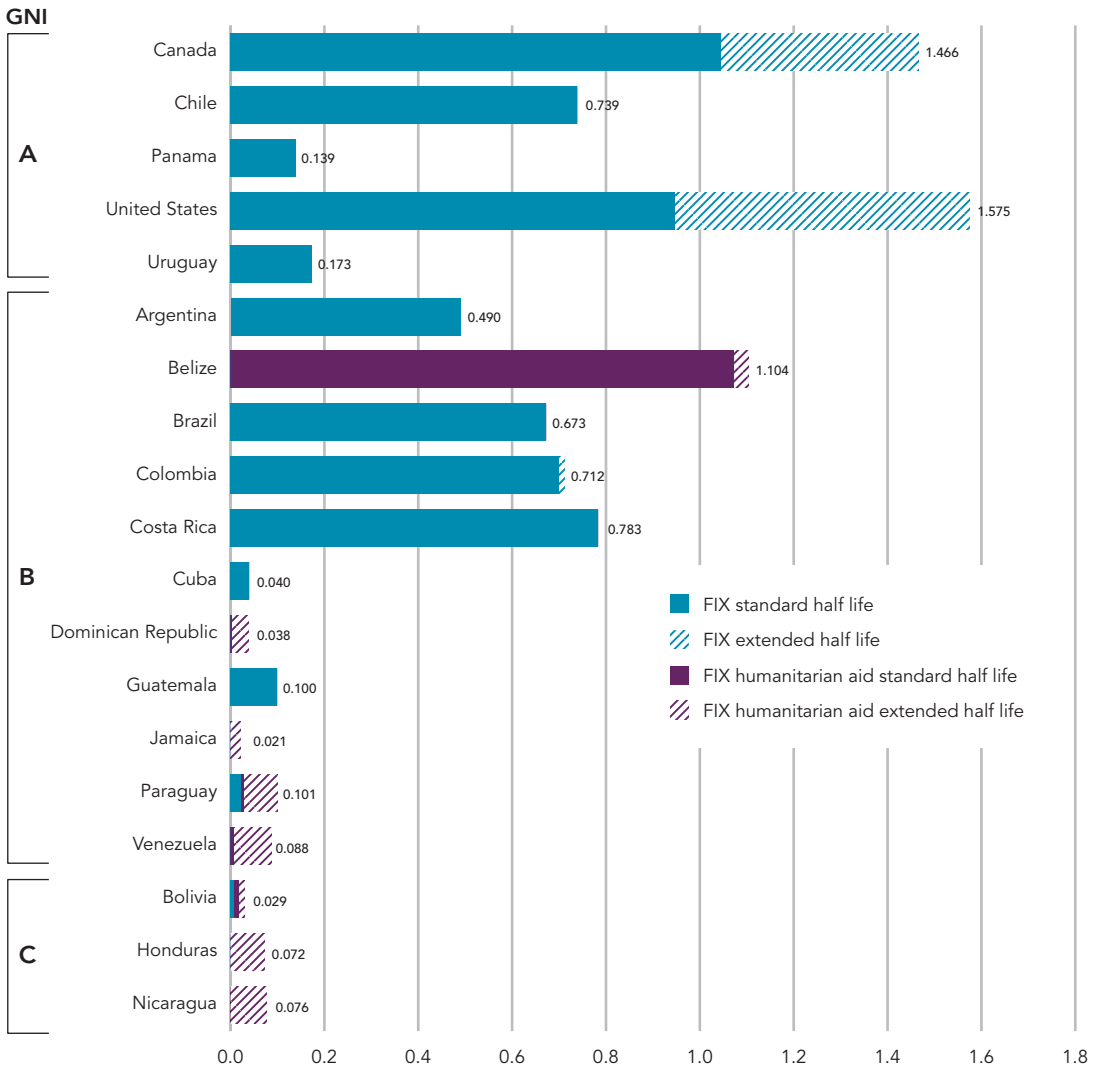
FIGURE F2a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

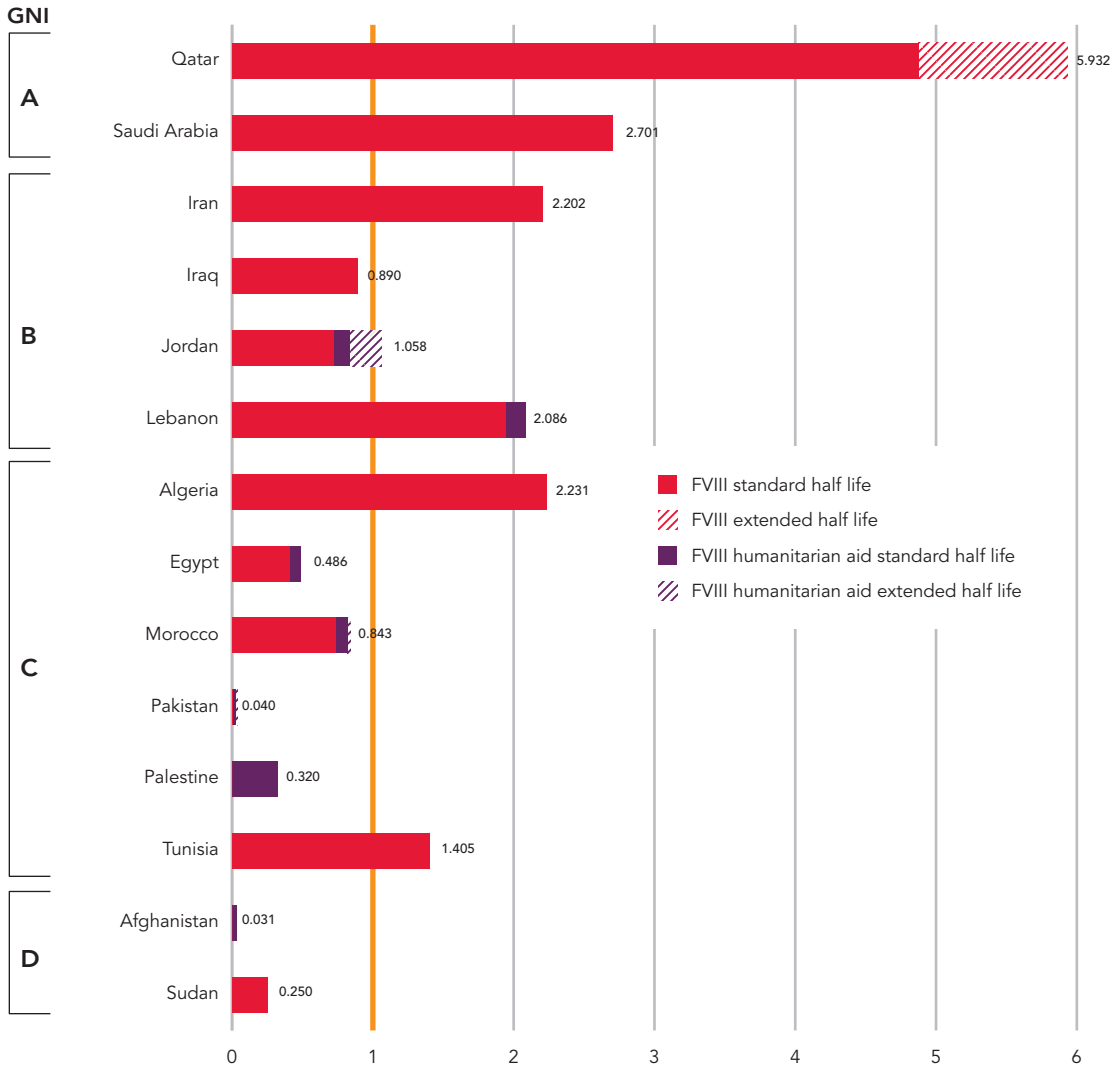
FIGURE F2b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

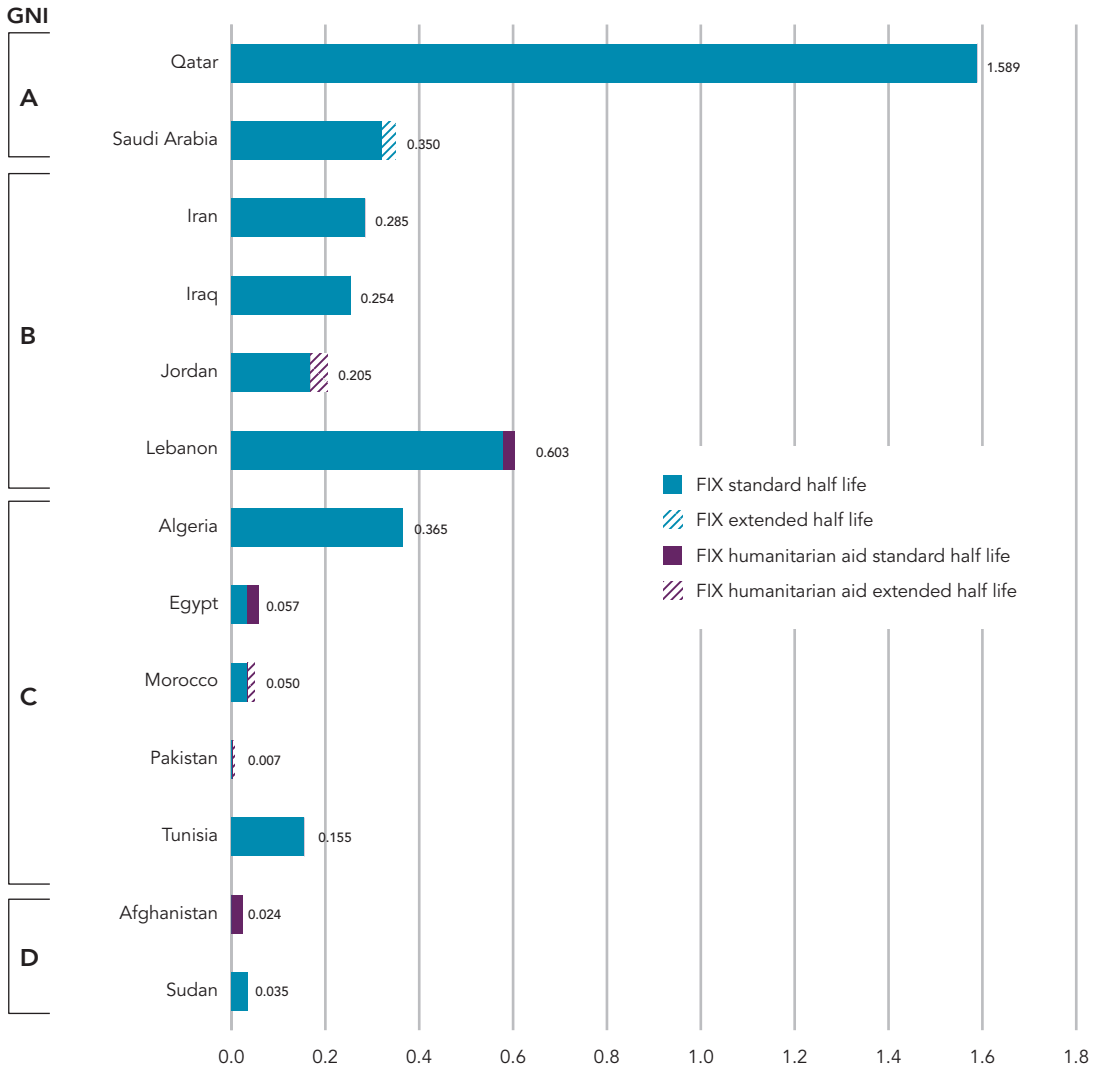
FIGURE F3a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

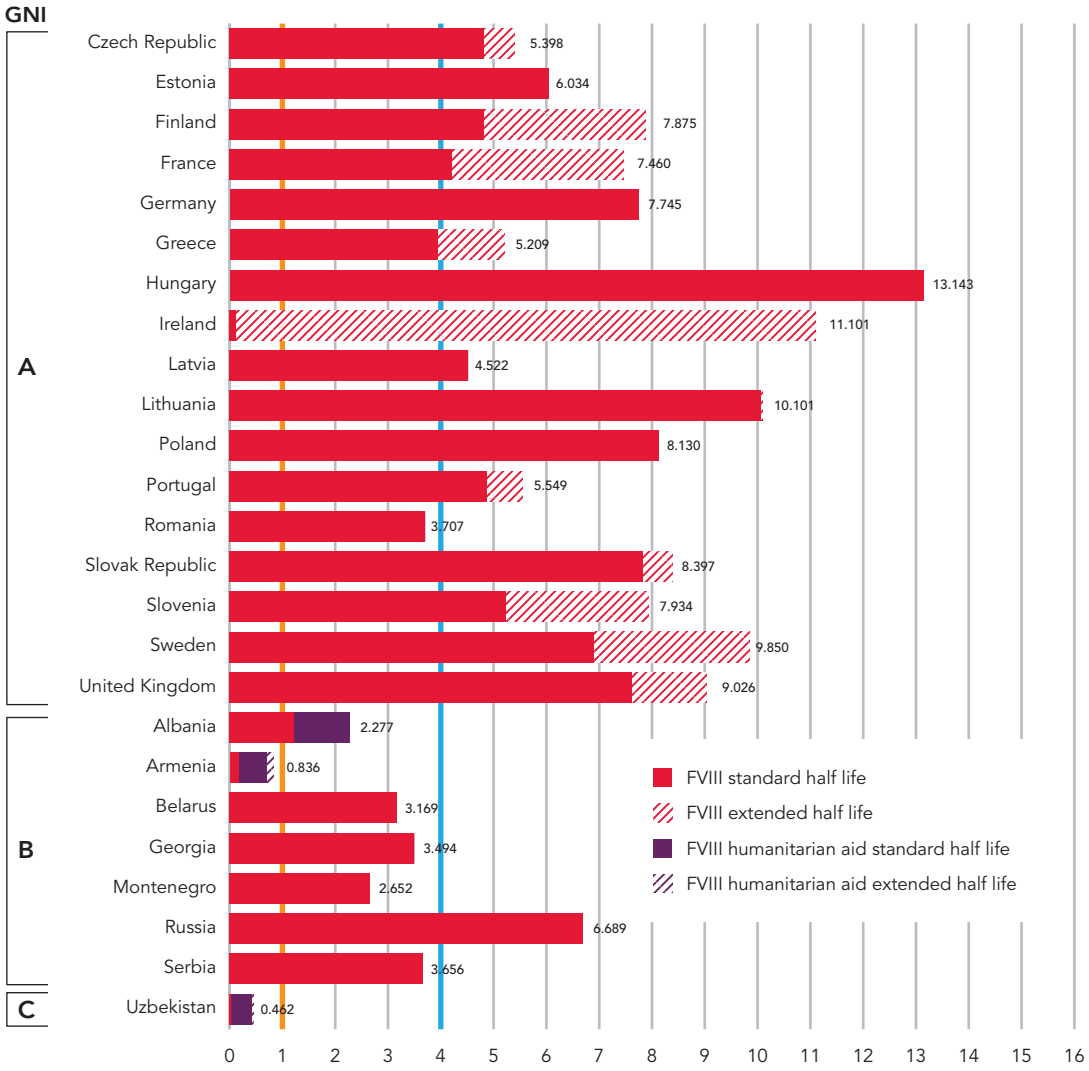
FIGURE F3b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

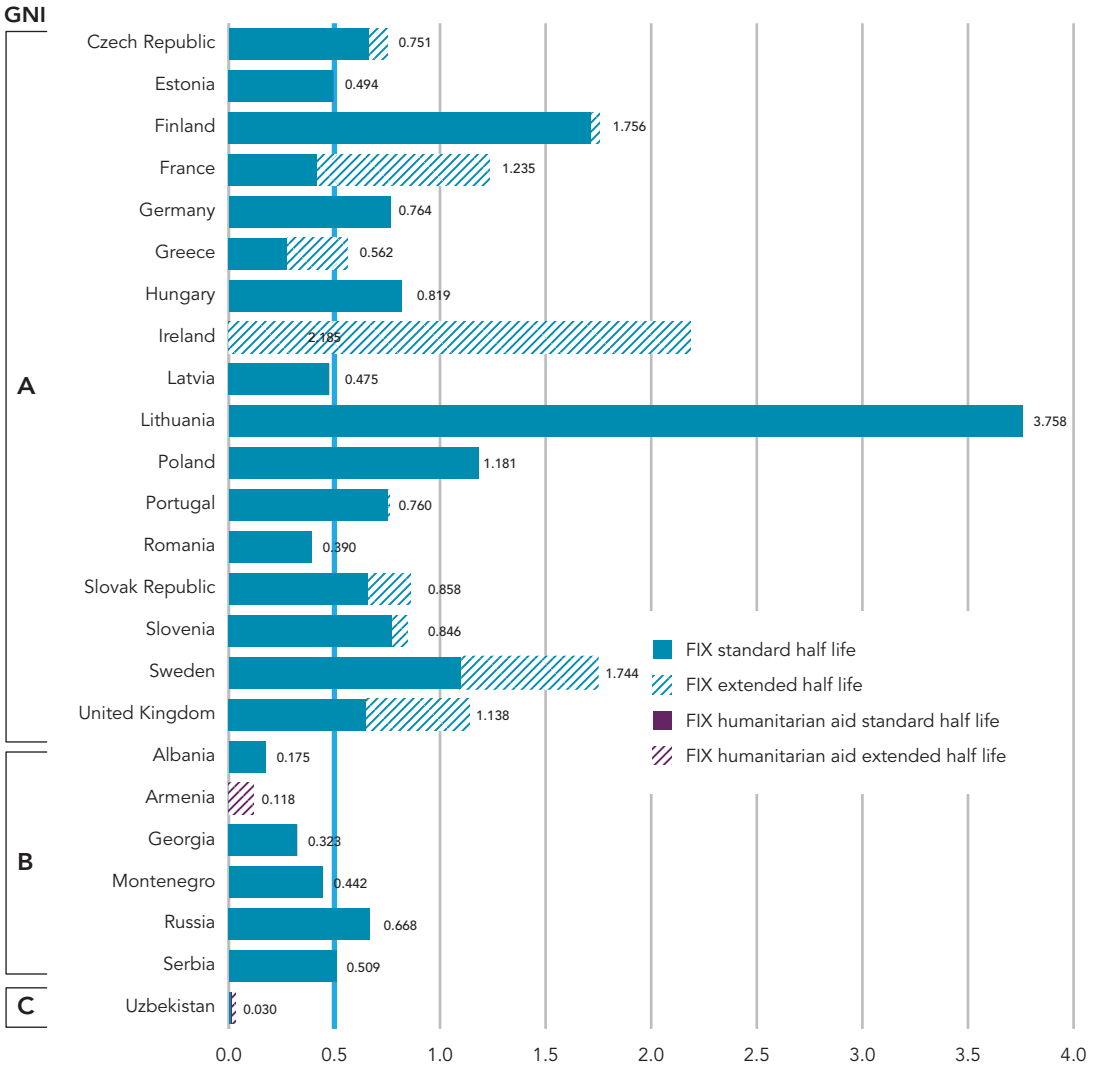
FIGURE F4a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: Europe**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. The European Department for the Quality of Medicines and Healthcare (EDQM) recommends the minimum consumption of factor VIII and IX concentrate in any country should be 4 IU and 0.5 IU per capita of general population respectively. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

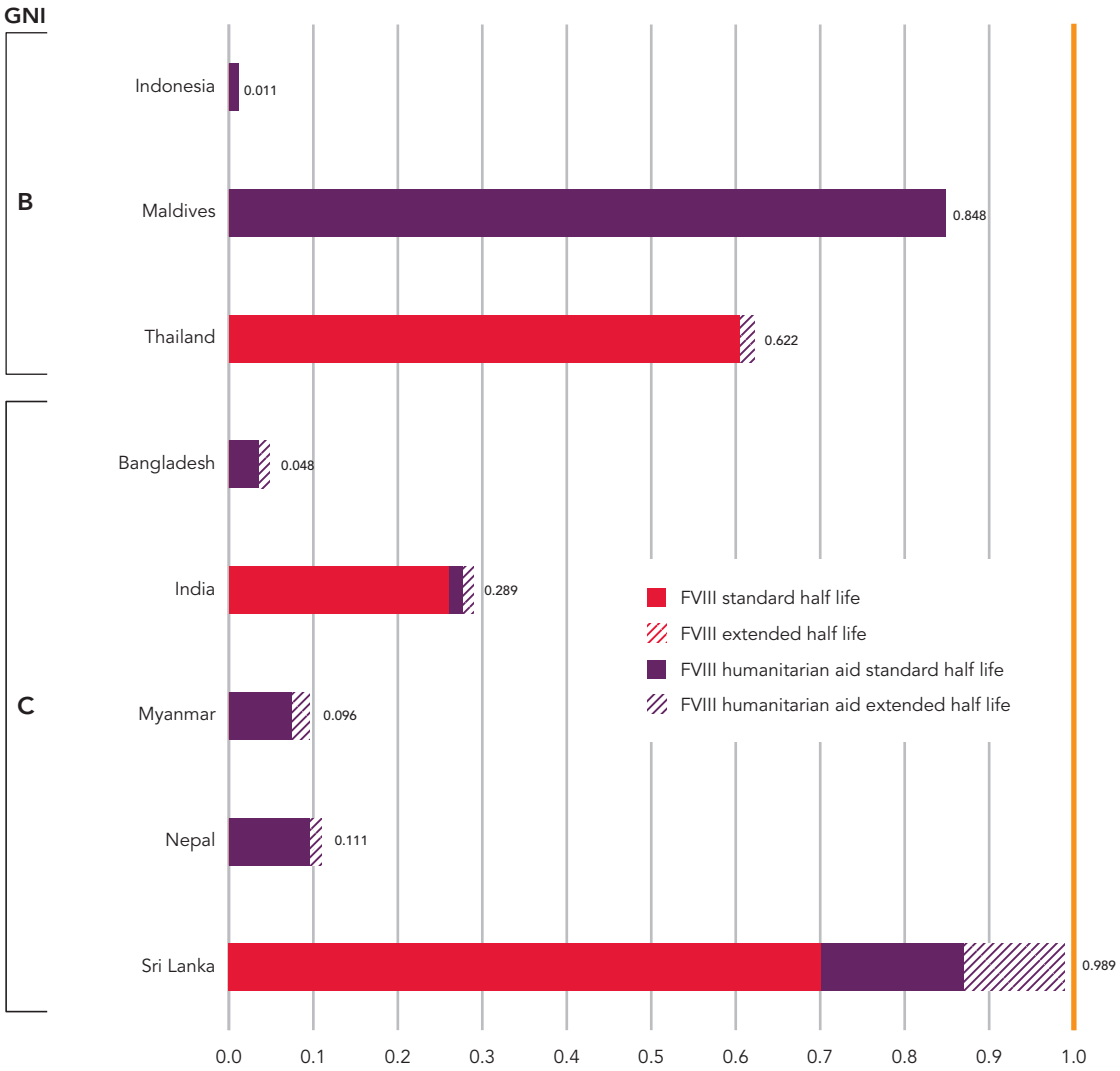
FIGURE F4b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: Europe**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products. The European Department for the Quality of Medicines and Healthcare (EDQM) recommends the minimum consumption of factor VIII and IX concentrate in any country should be 4 IU and 0.5 IU per capita of general population respectively.

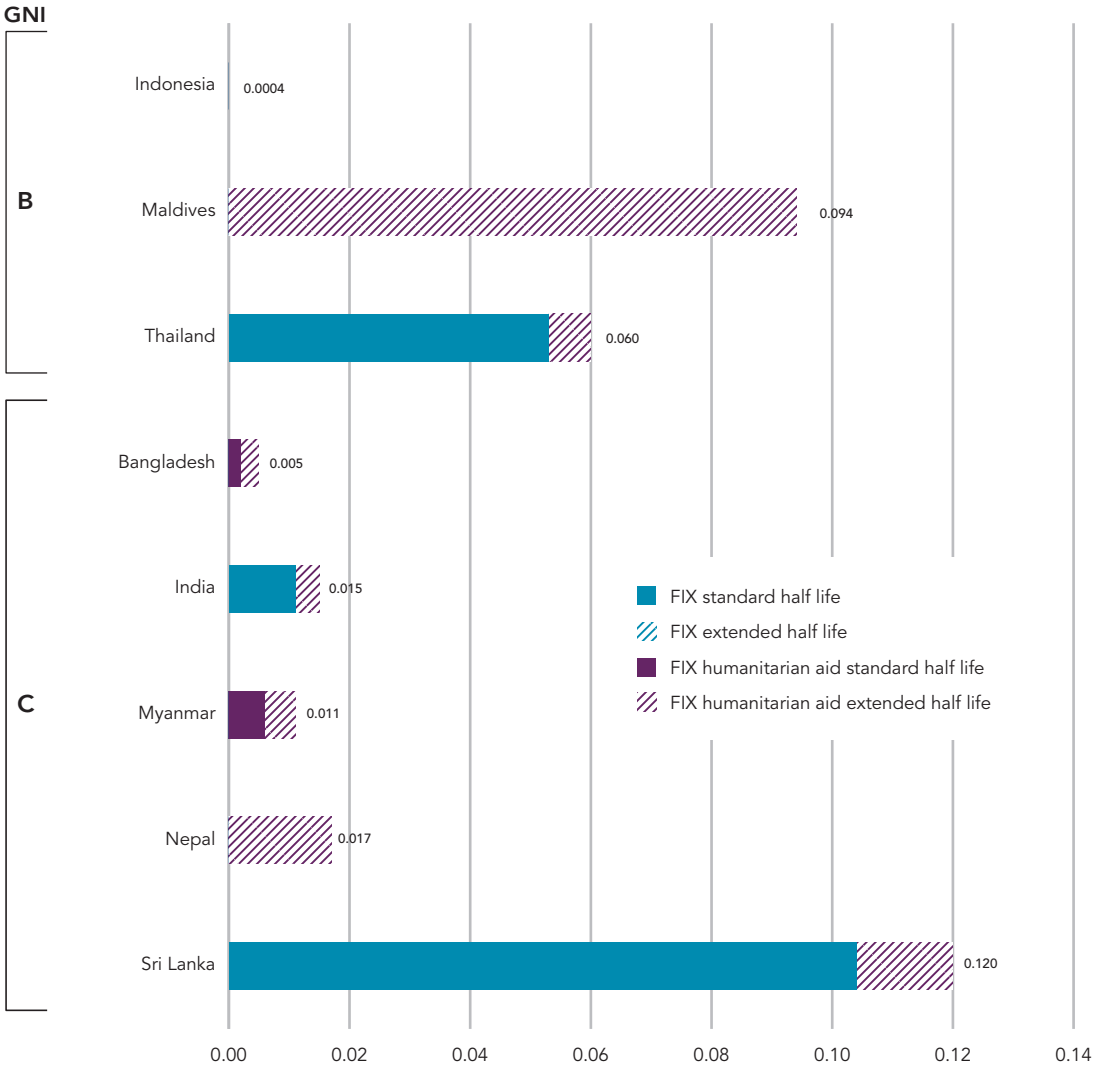
FIGURE F5a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

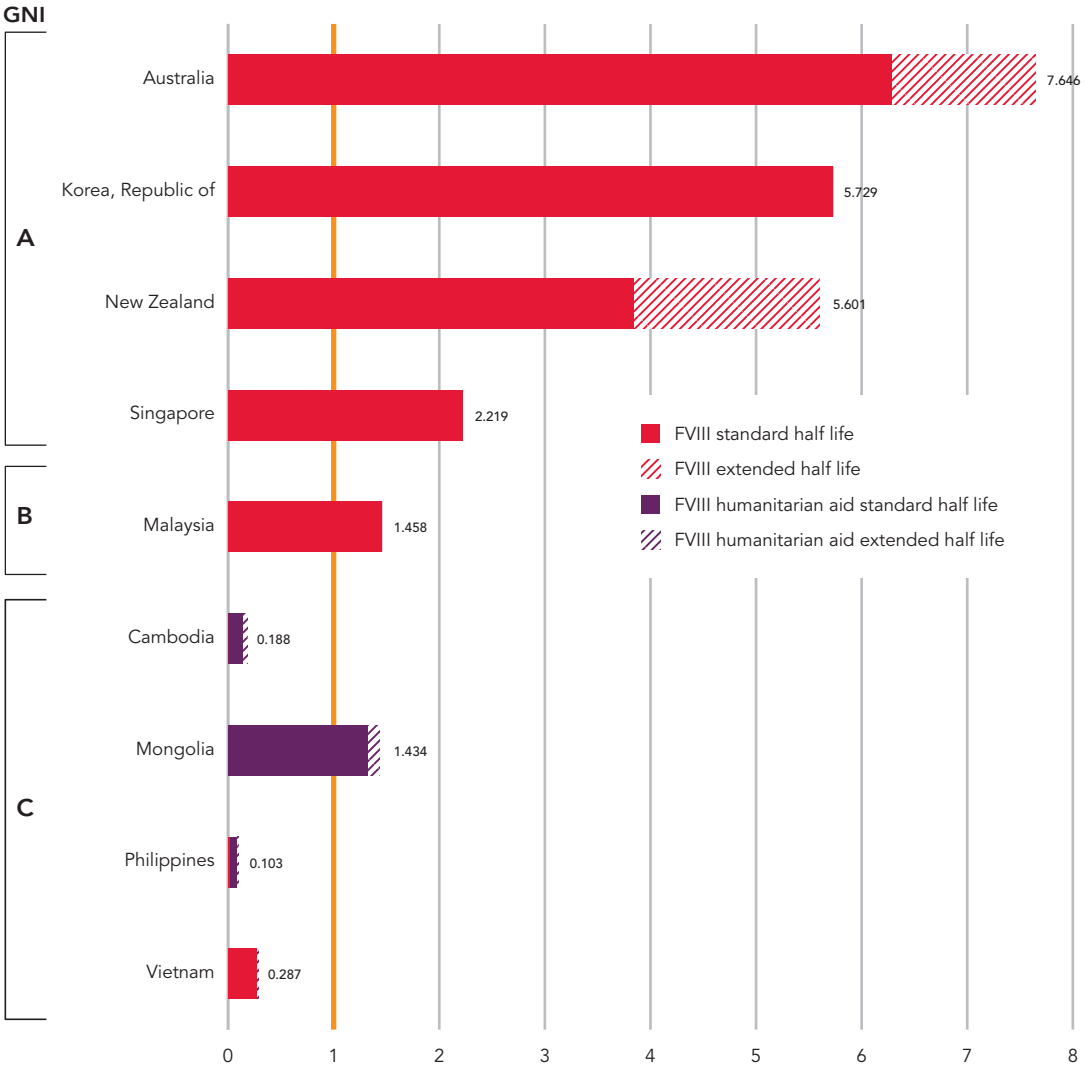
FIGURE F5b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

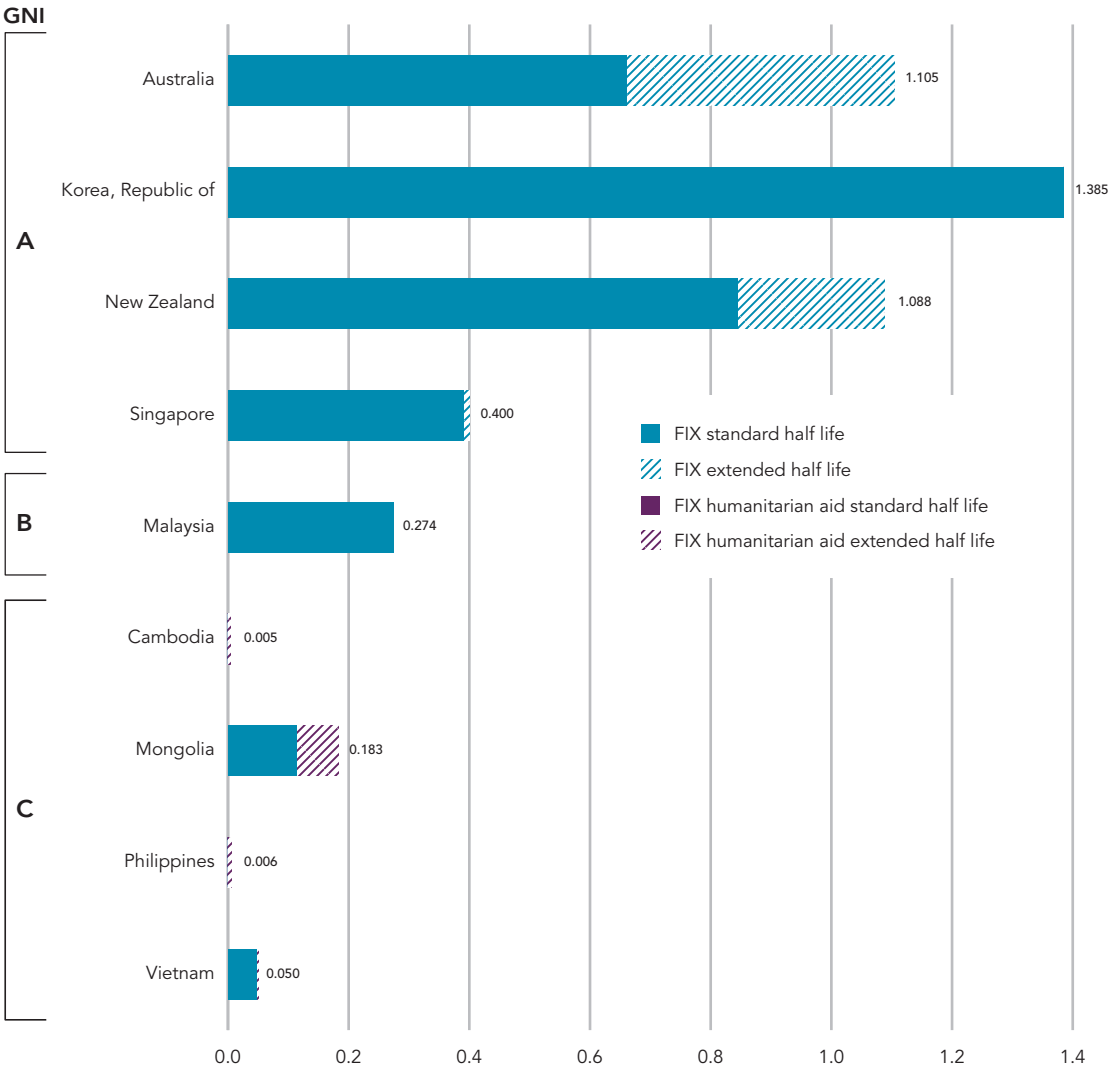
FIGURE F6a. **Mean per capita factor VIII use in 2019 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one IU of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

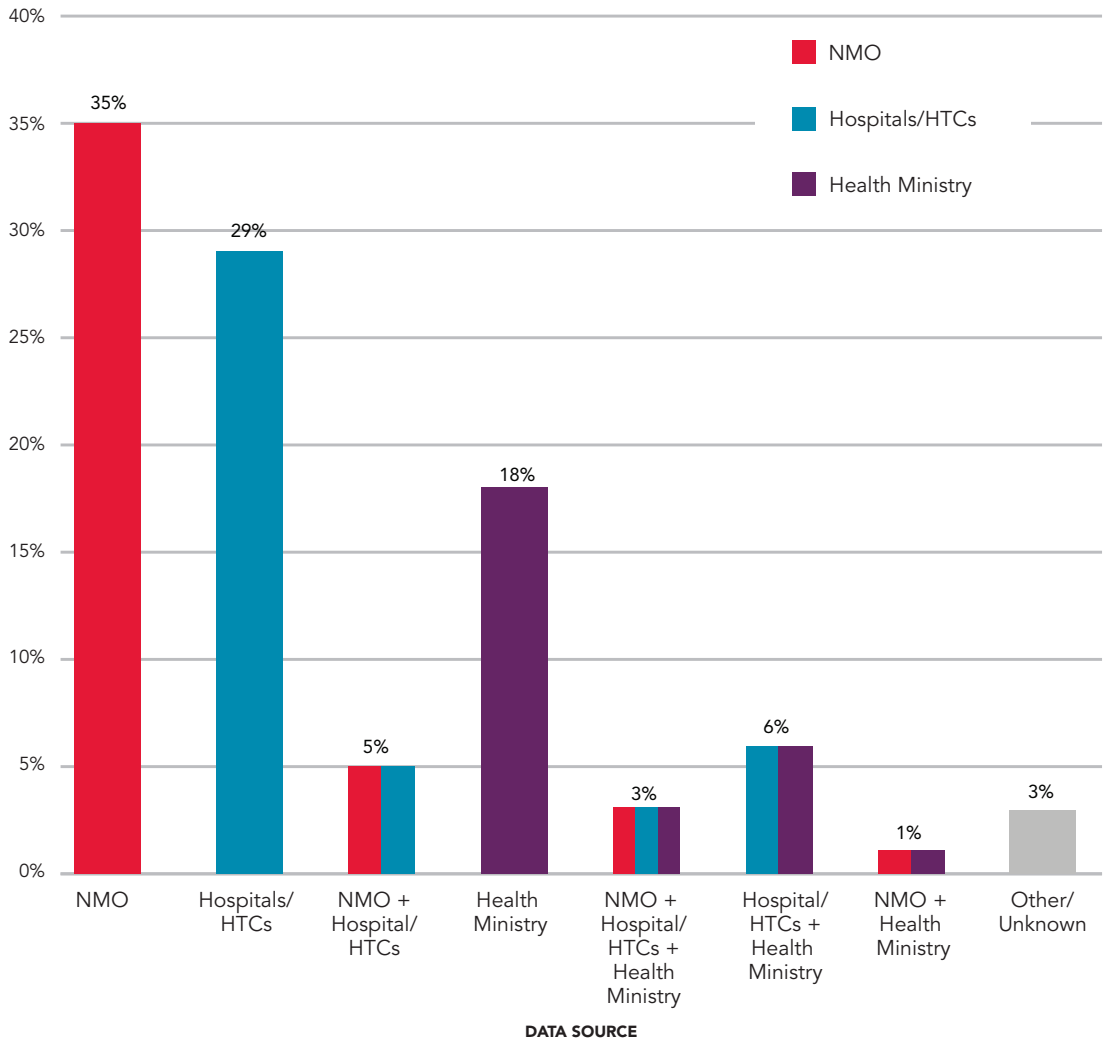
FIGURE F6b. **Mean per capita factor IX use in 2019 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2019 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

FIGURE G. **Data source**

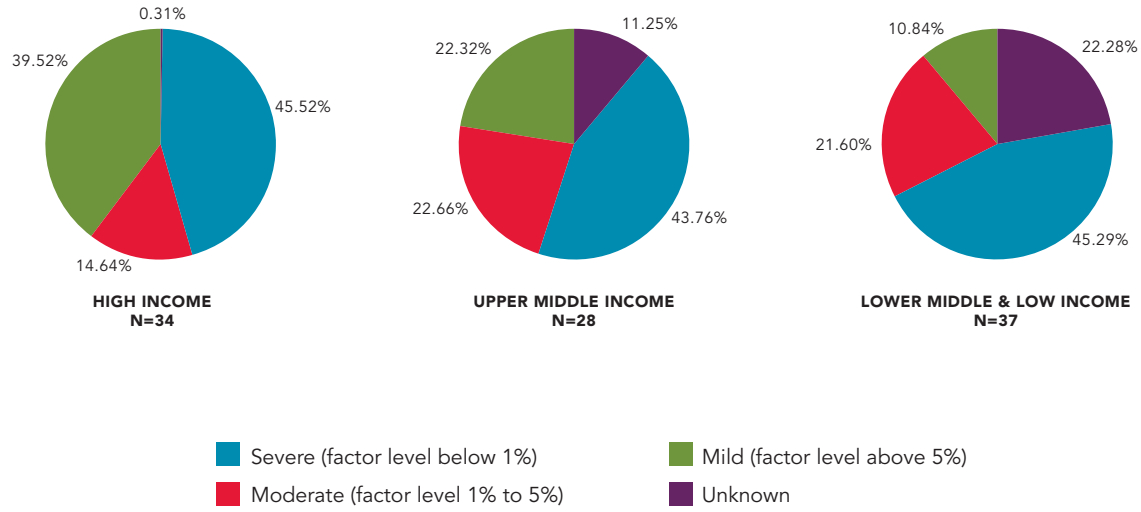


Members were asked the source of the numbers provided for the survey. Possible answers were: Hemophilia Society and/or NMO registry or database, Hospital(s)/HTC(s) registry or database, Health Ministry registry or database or Other. It is possible for members to have used multiple sources to obtain data.

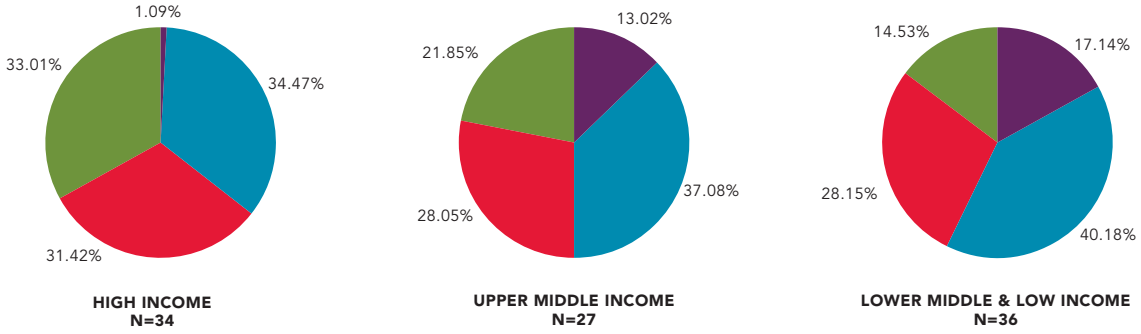
FIGURE H1. **Severity of hemophilia in males by GNI**

There are three levels of severity of hemophilia: mild, moderate and severe. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

Hemophilia A



Hemophilia B

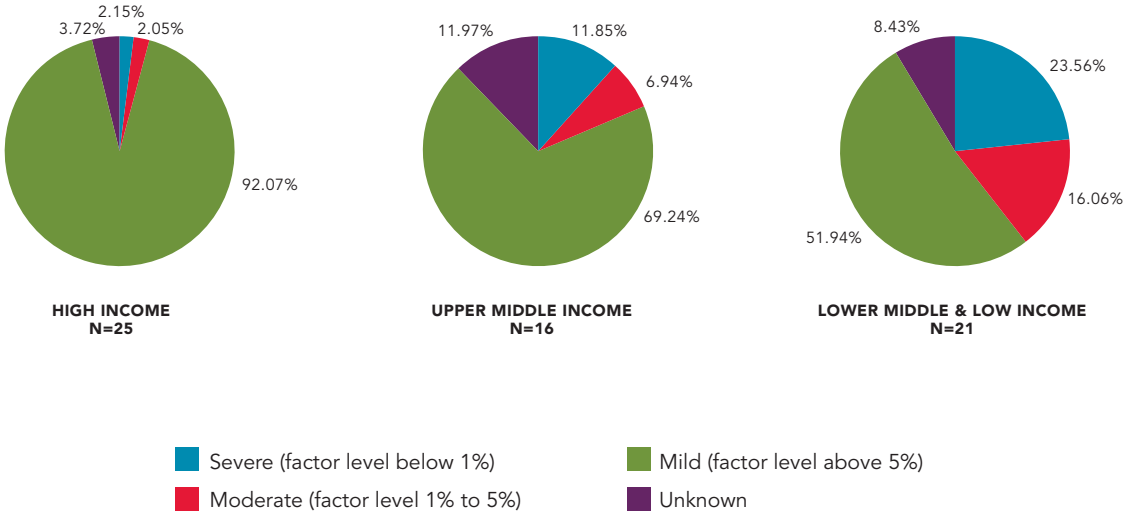


Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

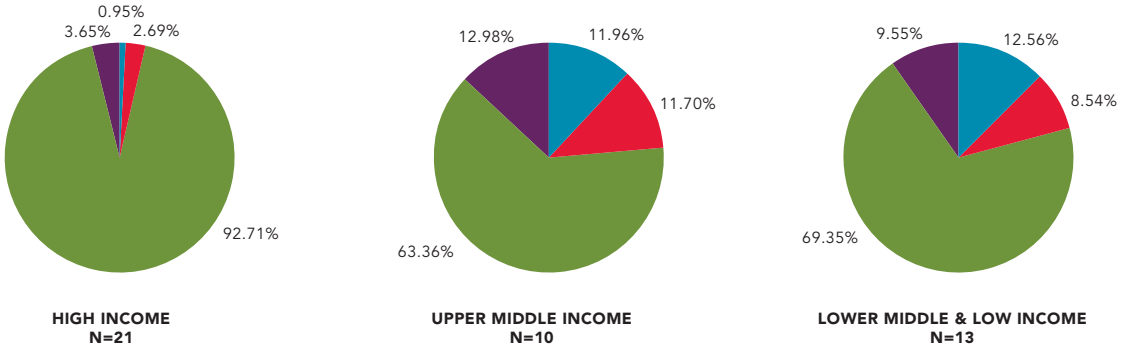
FIGURE H2. **Severity of hemophilia in females–by GNI**

There are three levels of severity of hemophilia: mild, moderate and severe. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

Hemophilia A



Hemophilia B



Economic category based on The World Bank Group 2019 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

TABLE 6. **National member organizations and their latest year of reporting.**

Please note: Not all of our members are able to submit data every year. The year indicates the latest year the data was submitted. For the 2019 survey report, 115 countries submitted data and can be found in **BOLD** in the table below.

Country	Last year of submission	Total number of submissions
Afghanistan	2019	4
Albania	2019	16
Algeria	2019	16
Argentina	2019	20
Armenia	2019	10
Australia	2019	21
Austria	2019	15
Azerbaijan	2018	14
Bahamas	2019	2
Bahrain	2014	5
Bangladesh	2019	21
Barbados	2019	3
Belarus	2019	13
Belgium	2019	19
Belize	2019	13
Benin	2018	1
Bolivia	2019	8
Bosnia-Herzegovina	2019	6
Botswana	2019	3
Brazil	2019	20
Bulgaria	2018	10
Burkina Faso	2019	4
Cambodia	2019	13
Cameroon	2019	13
Canada	2019	20
Chile	2019	12
China	2018	12
Colombia	2019	20
Costa Rica	2019	20
Cote d'Ivoire	2019	12
Croatia	2007	6
Cuba	2019	17

Country	Last year of submission	Total number of submissions
Cyprus	2013	7
Czech Republic	2019	14
Denmark	2018	14
Dominican Republic	2019	18
Ecuador	2018	14
Egypt	2019	18
El Salvador	2018	7
Eritrea	2019	12
Estonia	2019	11
Ethiopia	2019	9
Finland	2019	15
France	2019	17
Georgia	2019	18
Germany	2019	21
Ghana	2019	9
Greece	2019	20
Guatemala	2019	10
Guyana	2019	3
Honduras	2019	18
Hong Kong (China)	2018	3
Hungary	2019	18
Iceland	2007	6
India	2019	19
Indonesia	2019	16
Iran	2019	20
Iraq	2019	16
Ireland	2019	21
Israel	2019	14
Italy	2018	12
Jamaica	2019	10
Japan	2019	20
Jordan	2019	14

Country	Last year of submission	Total number of submissions
Kazakhstan	2008	1
Kenya	2019	18
Korea, Republic of	2019	21
Kuwait	2019	1
Kyrgyzstan	2018	7
Latvia	2019	21
Lebanon	2019	10
Lesotho	2019	13
Libya	N/A	0
Lithuania	2019	20
Luxembourg	2001	3
Macedonia	2018	9
Madagascar	2019	4
Malawi	2019	4
Malaysia	2019	19
Maldives	2019	6
Mali	2019	4
Mauritania	2019	3
Mauritius	2019	9
Mexico	2019	18
Moldova	2017	11
Mongolia	2019	13
Montenegro	2019	5
Morocco	2019	7
Mozambique	2019	3
Myanmar	2019	3
Namibia	2018	1
Nepal	2019	20
Netherlands	2019	15
New Zealand	2019	21
Nicaragua	2019	15
Nigeria	2019	12
Norway	2019	15
Oman	2016	6
Pakistan	2019	19
Palestine	2019	9
Panama	2019	18
Paraguay	2019	7
Peru	2015	10

Country	Last year of submission	Total number of submissions
Philippines	2019	17
Poland	2019	21
Portugal	2019	21
Qatar	2019	9
Romania	2019	16
Russia	2019	20
Saudi Arabia	2019	12
Senegal	2019	15
Serbia	2019	13
Singapore	2019	11
Slovak Republic	2019	18
Slovenia	2019	14
South Africa	2019	20
Spain	2013	13
Sri Lanka	2019	11
Sudan	2019	16
Suriname	2019	3
Sweden	2019	15
Switzerland	2017	16
Syria	2019	9
Tajikistan	2019	2
Tanzania	2019	8
Thailand	2019	19
Togo	2019	8
Trinidad and Tobago	2019	1
Tunisia	2019	15
Turkey	2014	16
Uganda	2019	9
Ukraine	2019	12
United Arab Emirates	2015	1
United Kingdom	2019	20
United States	2019	20
Uruguay	2019	12
Uzbekistan	2019	17
Venezuela	2019	21
Vietnam	2019	17
Zambia	2019	5
Zimbabwe	2019	15

TABLE 7. **Population statistics**

Please note: in all of the population charts a 0 indicates that the member organization reported the number zero and "Not Known" means that the member organization reported that they do not know the answer.

The population data is sourced from The World Bank Group.

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Afghanistan	38,041,754	457	2	0
Albania	2,854,191	233	6	8
Algeria	43,053,054	2,420	386	818
Argentina	44,938,712	2,771	397	10
Armenia	2,957,731	212	15	58
Australia	25,364,307	2,745	2,221	900
Austria	8,877,067	831	Not Known	Not Known
Bahamas	389,482	9	2	0
Bangladesh	163,046,161	2,106	4	3
Barbados	287,025	37	Not Known	3
Belarus	9,466,856	617	194	19
Belgium	11,484,055	1,267	2,106	535
Belize	390,353	38	Not Known	Not Known
Bolivia	11,513,100	180	3	3
Bosnia-Herzegovina	3,301,000	152	22	Not Known
Botswana	2,303,697	49	6	Not Known
Brazil	211,049,527	12,960	9,462	3,822
Burkina Faso	20,321,378	96	Not Known	Not Known
Cambodia	16,486,542	230	6	7
Cameroon	25,876,380	184	Not Known	149
Canada	37,589,262	3,810	4,522	2,277
Chile	18,952,038	1,763	492	825
Colombia	50,339,443	3,588	3,391	700
Costa Rica	5,047,561	218	94	86
Cote d'Ivoire	25,716,544	117	3	3
Cuba	11,333,483	490	398	3,644
Czech Republic	10,669,709	1,033	761	147
Dominican Republic	10,738,958	475	42	55
Egypt	100,388,073	6,197	597	1,391

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Eritrea	5,869,869	64	Not Known	Not Known
Estonia	1,326,590	117	118	110
Ethiopia	112,078,730	332	0	0
Finland	5,520,314	253	553	Not Known
France	67,059,887	8,330	2,742	1,120
Georgia	3,720,382	326	43	41
Germany	83,132,799	4,523	4,505	Not Known
Ghana	30,417,856	341	9	Not Known
Greece	10,716,322	1,025	1,212	553
Guatemala	16,604,026	327	23	2
Guyana	782,766	17	Not Known	Not Known
Honduras	9,746,117	376	19	2
Hungary	9,769,949	1,108	1,378	601
India	1,366,417,754	23,666	760	521
Indonesia	270,625,568	2,684	22	0
Iran	82,913,906	10,030	1,678	3,639
Iraq	39,309,783	2,416	507	550
Ireland	4,941,444	915	1,644	1,305
Israel	9,053,300	724	175	723
Jamaica	2,948,279	60	3	8
Japan	126,264,931	6,596	1,363	387
Jordan	10,101,694	447	259	255
Kenya	52,573,973	650	33	15
Korea, Republic of	51,709,098	2,180	146	167
Kuwait	4,207,083	36	5	28
Latvia	1,912,789	79	65	11
Lebanon	6,855,713	223	163	72
Lesotho	2,125,268	24	Not Known	2
Lithuania	2,786,844	183	306	17
Madagascar	26,969,307	133	2	14
Malawi	18,628,747	70	Not Known	Not Known
Malaysia	31,949,777	1,127	141	78
Maldives	530,953	18	Not Known	Not Known
Mali	19,658,031	154	19	4
Mauritania	4,525,696	81	1	1
Mauritius	1,265,711	87	1	10

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Mexico	127,575,529	5,853	339	61
Mongolia	3,225,167	110	14	0
Montenegro	622,137	46	3	5
Morocco	36,471,769	868	157	172
Mozambique	30,366,036	100	1	2
Myanmar	54,045,420	693	23	5
Nepal	28,608,710	710	9	35
Netherlands	17,332,850	1,277	346	82
New Zealand	4,917,000	590	95	70
Nicaragua	6,545,502	350	91	20
Nigeria	200,963,599	465	12	0
Norway	5,347,896	435	614	79
Pakistan	216,565,318	2,233	340	145
Palestine	4,685,306	354	30	35
Panama	4,246,439	314	515	101
Paraguay	7,044,636	434	0	0
Philippines	108,116,615	1,566	46	0
Poland	37,970,874	3,026	2,200	948
Portugal	10,269,417	945	853	857
Qatar	2,832,067	57	42	13
Romania	19,356,544	1,825	87	7
Russia	144,373,535	7,706	2,204	Not Known
Saudi Arabia	34,268,528	637	241	336
Senegal	16,296,364	274	10	14
Serbia	6,944,975	556	313	72
Singapore	5,703,569	269	95	79
Slovak Republic	5,454,073	611	733	1,187
Slovenia	2,087,946	251	189	86
South Africa	58,558,270	2,345	654	233
Sri Lanka	21,803,000	1,095	63	53
Sudan	42,813,238	1,285	333	433
Suriname	581,372	15	3	0
Sweden	10,285,453	972	286	Not Known
Syria	17,070,135	907	116	186
Tajikistan	9,321,018	580	40	620
Tanzania	58,005,463	139	1	Not Known

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Thailand	69,625,582	1,763	225	241
Togo	8,082,366	47	Not Known	Not Known
Trinidad and Tobago	1,394,973	94	10	1
Tunisia	11,694,719	550	226	460
Uganda	44,269,594	273	3	0
Ukraine	44,385,155	2,188	469	Not Known
United Kingdom	66,834,405	8,397	11,066	10,258
United States	328,239,523	18,008	12,394	4,809
Uruguay	3,461,734	257	263	17
Uzbekistan	33,580,650	1,611	158	43
Venezuela	28,515,829	2,873	1,177	1,118
Vietnam	96,462,106	3,940	181	501
Zambia	17,861,030	189	5	Not Known
Zimbabwe	14,645,468	173	Not Known	Not Known

TABLE 8. **Distribution of reported bleeding disorders by country**

Please note: in all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Afghanistan	413	44		2												
Albania	200	33	0	6	0	0	0	0	4	2	0	2				
Algeria	1,980	440		386	64	10	81	30	484	35	19	19	31	30	15	
Argentina	2,393	378	0	397	0	0	0	1	2	0	1	1	0	2	0	3
Armenia	190	22		15	2	0	1	3	21	1	3	1	12	4	6	4
Australia	2,226	519	0	2,221	113		18		87	18	298	43		27	10	286
Austria	693	138	0													
Bahamas	7	1	1	2												
Bangladesh	1,761	339	6	4	2	0	0	0	0	0	0	1	0	0	0	0
Barbados	24	13	0				2	1								
Belarus	499	118		194					19							
Belgium	1,015	243	9	2,106	2	2	21	0	148	10	143	4	93	20	4	88
Belize	14	5	19													
Bolivia	146	34		3					3							
Bosnia-Herzegovina	130	22		22												
Botswana	41	8	0	6												
Brazil	10,821	2,139	0	9,462	147	21	262	45	1,577	151	305	84	0	623	109	498
Burkina Faso	71	25														
Cambodia	197	33		6								1				6
Cameroon	149	28	7					149								
Canada	3,127	683	0	4,522	169	16	82	0	508	54	509	56	0	28	68	787
Chile	1,516	170	77	492	0	0	24	7	318	17	49	3	2	7	4	394
Colombia	2,958	630	0	3,391	67	17	67	52	185	37	119	69	36	15	2	34
Costa Rica	182	36		94	4		2	13	46	12	7	2				
Cote d'Ivoire	100	17	0	3	0	0	0	0	1	2	0	0	0	0	0	0
Cuba	412	78	0	398	3	1	2	0	2	0	10	7	16	2	0	3,601
Czech Republic	895	138	0	761	0	4	10	0	82	6	28	1	16			
Dominican Republic	396	48	31	42					9	39		5		2		
Egypt	5,031	1,166	0	597	167	8	185	8	207	118	101	45	5	496	51	0
Eritrea	57	7														
Estonia	106	11		118	12	1	6	1	32		7		31		2	18

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Ethiopia	157	30	145													
Finland	168	31	54	553												
France	6,727	1,603		2,742	41	1	56	20	208	30	234	33	0	226	56	215
Georgia	272	54		43	1		1		23	1		2		6		7
Germany	3,811	712		4,505												
Ghana	306	25	10	9												
Greece	839	186	0	1,212	37	2	36	1	184	16	109	11	0	19	11	127
Guatemala	253	34	40	23							1			1		
Guyana	16	1														
Honduras	314	35	27	19								2				
Hungary	871	237		1,378	18	2	25		372	23	85	4		3	1	68
India	19,690	3,150	826	760	27	12	57	13	78	62	41	125		86	20	
Indonesia	2,214	347	123	22												
Iran	5,271	1,118	3,641	1,678	164	28	266	255	860	222	278	278	243	617	105	323
Iraq	1,908	508		507	60	2	15	4	145	30	14	62		118	23	77
Ireland	664	251	0	1,644	88	3	175	1	220	153	271	11	0	14	4	365
Israel	618	106		175	5	0	9	14	90	9	374	8		44	5	165
Jamaica	56	4		3						5				1		2
Japan	5,410	1,186		1,363	84	7	45	9	107	22	39	74				
Jordan	341	106	0	259	1	4	12	0	51	21	37	17		112		
Kenya	528	122	0	33	0	0	0	0	2	0	1	0	0	0	0	12
Korea, Republic of	1,746	434	0	146	8	0	7	3	49	2	25	5	68			
Kuwait	30	6	0	5		2			7	1	3	7		4	3	1
Latvia	66	13		65			2		6	1				1		1
Lebanon	175	48	0	163	35	0	9	1	7	5	5	4	0	1	0	5
Lesotho	20	2	2								2					
Lithuania	156	26	1	306					12	2						3
Madagascar	73	60	0	2	14											
Malawi	38	8	24													
Malaysia	950	177	0	141	0	4	4	0	10	11	9	11	0	24	3	2
Maldives	14	4														
Mali	132	12	10	19	1	0	0	0	1	0	0	1	0	0	0	1
Mauritania	64	17		1										1		
Mauritius	76	11	0	1	0	0	0	0	4	1	0	0	2	3	0	0
Mexico	4,809	730	314	339	2	1	3	0	29	5	4	4	5	4	0	4
Mongolia	81	29		14												
Montenegro	42	4	0	3	0	0	0	0	1	0	1	3	0	0	0	0

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Morocco	722	146		157	18	7	15	9	64	13	3	7	0	28	2	6
Mozambique	98	2		1	0	0	1		1	0	0	0		0	0	0
Myanmar	587	99	7	23					2	2	1					
Nepal	571	104	35	9			2	1	7	22		3				
Netherlands	1,115	162		346	8	3	4	1	17	2	10	9	1	8		19
New Zealand	478	112	0	95	10	2	4	0	14	3	13	10	0	6	4	4
Nicaragua	295	55	0	91	0	0	0	0	0	0	0	0	18	2	0	0
Nigeria	413	14	38	12	0	0	0	0	0	0	0	0	0	0	0	0
Norway	343	92	0	614	3	2	4	0	37	4	1	5	0	12	4	7
Pakistan	1,890	343	0	340	10	4	19	3	35	25	1	25	1	20	2	0
Palestine	305	49		30			8		2				23	2		
Panama	277	37		515					9	16				11	1	64
Paraguay	395	39														
Philippines	1,155	201	210	46												
Poland	2,562	464	0	2,200	146	1	33	3	329	29	79	13	0	30	12	273
Portugal	744	201		853	24	4	31	4	291	24	167	10	26	33	26	217
Qatar	49	8	0	42	0	0	0	0	3	1	0	2	0	0	5	2
Romania	1,615	210		87	2			1	2		2					
Russia	6,525	1,181		2,204												
Saudi Arabia	511	126	0	241	5	18	31	2	27	24	15	60	0	121	10	23
Senegal	241	33		10	1	0	1	0	4	1	0	1		2		4
Serbia	468	88	0	313	9	0	4	2	37	1	11	5	1	0	2	0
Singapore	226	43	0	95	0	0	15	0	9	0	50	5	0	0	0	0
Slovak Republic	529	82	0	733	108	0	78	1	850	38	59	5	0	10	15	23
Slovenia	220	31	0	189	4	0	12	3	17	2	21	0	0	7	0	20
South Africa	1,967	378	0	654	7	5	43	5	18	13	33	9	0	22	27	51
Sri Lanka	883	212		63	1	2	10	1	3	1	10	6		10		9
Sudan	1,036	249		333	59	1	59	3	47	30	7	28		9	16	174
Suriname	15	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0
Sweden	769	203		286												
Syria	814	93	0	116	19	0	16	34	37	4	0	1	1	41	5	28
Tajikistan	520	60		40	0	0	0	0	0	520	60	40	0	0	0	0
Tanzania	90	13	36	1												
Thailand	1,557	206		225	4	3	12	5	57	9	9	18	0	55	9	60
Togo	34	8	5													
Trinidad and Tobago	78	16		10						1						

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Tunisia	437	113	0	226	46	0	18	7	139	16	117	41	9	48	7	12
Uganda	235	36	2	3												
Ukraine	1,860	328	0	469												
United Kingdom	6,860	1,537	0	11,066	901	16	248	27	1,735	297	3,609	81	0	152	98	3,094
United States	13,915	4,093		12,394	210	47	113	15	1,019	137	574	108	2,365	180	41	
Uruguay	209	41	7	263			1		6		9			1		
Uzbekistan	1,437	164	10	158					10		6	6		19	2	
Venezuela	2,275	598	0	1,177	23	67	42	29	180	112	402	16	18	27	5	197
Vietnam	3,248	692	0	181	4	7	17	15	73	26	24	17	3	106	2	207
Zambia	129	28	32	5												
Zimbabwe	159	14														
TOTAL	**157,517**	**31,997**	**5,749**	**80,302**	**2,960**	**337**	**2,326**	**802**	**11,282**	**2,497**	**8,425**	**1,537**	**3,026**	**3,503**	**797**	**11,591**

TABLE 9. **Sex distribution**

This table provides the number of males and females with each bleeding disorder from the countries that have reported sex data. Total percentages may not add up to 100% as some countries have not provided complete information on sex distribution of their patients.

Disorders	Countries reporting	Total patients identifed	Male	Percent male	Female	Percent female	Sex not known	Percent not known
Hemophilia A	**115**	157,517	137,574	**87**	5,604	**4**	6,580	**4**
Hemophilia B	**115**	31,997	27,416	**86**	1,907	**6**	1,204	**4**
Hemophilia type unknown	**73**	5,749	3,754	**65**	174	**3**	113	**2**
von Willebrand disease (VWD)	**101**	80,302	26,774	**33**	44,380	**55**	2,699	**3**
Factor I Deficiency	**67**	2,960	1,334	**45**	1,569	**53**	1	**0**
Factor II Deficiency	**63**	337	161	**48**	167	**50**	0	**0**
Factor V Deficiency	**70**	2,326	1,088	**47**	1,181	**51**	6	**0**
Factor V+VIII Deficiency	**65**	802	326	**41**	310	**39**	0	**0**
Factor VII Deficiency	**78**	11,282	5,440	**48**	5,556	**49**	15	**0**
Factor X Deficiency	**73**	2,497	1,517	**61**	931	**37**	1	**0**
Factor XI Deficiency	**71**	8,425	3,498	**42**	4,372	**52**	380	**5**
Factor XIII Deficiency	**70**	1,537	852	**55**	602	**39**	0	**0**
Bleeding disoder: type unknown	**52**	3,026	1,147	**38**	1,828	**60**	19	**1**
Platelet disorder: Glanzmann's Thrombasthenia	**69**	3,503	1,611	**46**	1,832	**52**	6	**0**
Platelet disorder: Bernard-Soulier Syndrome	**58**	797	344	**43**	391	**49**	46	**6**
Platelet Disorders: Other/Unknown	**62**	11,591	2,568	**22**	4,597	**40**	4,340	**37**

A woman who has ≤40% of the normal level of clotting factor (FVIII – hemophilia A, FIX – hemophilia B) is considered to be a person with hemophilia. A woman with more than 40 percent clotting factor is considered a carrier and is not included in this report.

TABLE 10. **Number of inhibitor cases in Hemophilia A and B**

(95 countries reported number of inhibitors)

Patients with current clinically significant inhibitors refers to patients who do not respond to standard treatment.

Please note: a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Albania	18	6	2	0
Algeria	69	14	0	0
Argentina	72	6	7	0
Armenia	12	6	1	No data
Australia	66	4	5	2
Austria	22	No data	0	No data
Bahamas	1	0	0	0
Bangladesh	6	2	4	1
Barbados	1	1	1	1
Belarus	48	1	8	No data
Bolivia	3	No data	No data	No data
Bosnia-Herzegovina	7	No data	No data	No data
Botswana	3	0	0	0
Brazil	439	63	33	21
Burkina Faso	1	0	0	0
Cambodia	7	4	0	0
Cameroon	13	No data	4	No data
Canada	69	9	4	1
Chile	30	2	3	0
Colombia	291	18	5	0
Costa Rica	22	0	0	0
Cote d'Ivoire	4	0	1	1
Cuba	25	1	0	0
Czech Republic	26	3	2	0
Egypt	340	106	2	0
Eritrea	1	1	0	0
Estonia	4	0	0	0

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Finland	12	1	0	0
France	179	7	14	0
Georgia	10	No data	No data	No data
Germany	135	No data	9	No data
Ghana	No data	1	No data	No data
Greece	19	4	2	0
Guatemala	15	15	No data	No data
Honduras	12	1	0	0
Hungary	No data	21	No data	No data
India	904	No data	19	No data
Indonesia	73	0	1	1
Iran	348	4	28	2
Iraq	200	7	7	1
Ireland	10	0	3	0
Israel	19	3	2	No data
Jamaica	11	1	No data	No data
Jordan	24	No data	1	No data
Kenya	6	2	0	0
Korea, Republic of	49	2	4	0
Kuwait	6	2	0	0
Lebanon	9	1	0	0
Lithuania	8	1	No data	No data
Madagascar	5	0	1	0
Malaysia	64	2	6	0
Maldives	1	1	No data	No data
Mali	2	1	0	0
Mauritius	1	0	0	0
Montenegro	2	1	0	0
Morocco	124	17	5	1
Mozambique	3	1	No data	0
Myanmar	50	21	0	0
Nepal	16	0	No data	No data
Nicaragua	5	0	0	0
Nigeria	0	0	0	0
Norway	11	1	0	No data

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Pakistan	15	0	1	0
Palestine	3	No data	No data	No data
Panama	9	1	0	0
Paraguay	1	1	No data	No data
Philippines	26	4	2	0
Poland	148	No data	4	No data
Portugal	32	4	1	0
Qatar	3	1	0	0
Romania	91	1	No data	No data
Saudi Arabia	100	0	2	0
Senegal	11	2	0	0
Serbia	15	0	0	0
Singapore	5	1	0	0
Slovak Republic	5	0	0	0
Slovenia	4	1	1	1
South Africa	173	No data	12	No data
Sri Lanka	94	14	No data	No data
Sudan	8	1	No data	No data
Suriname	0	0	0	0
Sweden	30	No data	2	No data
Syria	72	2	1	0
Tajikistan	10	10	No data	No data
Thailand	60	10	4	1
Togo	1	No data	No data	No data
Trinidad and Tobago	24	No data	2	No data
Tunisia	23	3	5	1
Uganda	3	3	No data	No data
United Kingdom	228	21	12	1
United States	914	No data	94	No data
Uruguay	9	0	2	0
Uzbekistan	23	6	No data	No data
Venezuela	102	0	1	0
Vietnam	131	16	0	0
TOTAL	**6,306**	**467**	**330**	**36**

TABLE 11. **Age distribution: Hemophilia A**

(101 countries reported age data for hemophilia A)

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	413	2%	48%	25%	24%	0%	0%
Albania	200	4%	21%	12%	45%	19%	0%
Argentina	2,393	3%	15%	9%	46%	24%	3%
Armenia	132	7%	33%	3%	45%	12%	0%
Australia	2,226	5%	15%	7%	38%	34%	0%
Austria	693	3%	9%	8%	42%	38%	0%
Bahamas	7	0%	14%	0%	71%	14%	0%
Bangladesh	1,761	13%	33%	20%	31%	3%	0%
Barbados	24	8%	13%	8%	58%	13%	0%
Belgium	1,015	3%	10%	9%	35%	43%	0%
Belize	14	7%	21%	29%	43%	0%	0%
Bolivia	143	6%	38%	13%	41%	3%	0%
Botswana	41	20%	24%	22%	32%	2%	0%
Brazil	10,821	5%	15%	9%	50%	20%	0%
Burkina Faso	71	35%	42%	7%	11%	1%	3%
Cambodia	197	6%	47%	22%	23%	0%	3%
Cameroon	152	25%	28%	29%	13%	1%	5%
Canada	3,127	3%	12%	8%	42%	36%	0%
Chile	1,516	3%	15%	11%	49%	21%	0%
Colombia	2,958	6%	11%	11%	60%	11%	0%
Costa Rica	182	5%	16%	13%	53%	13%	0%
Cote d'Ivoire	100	15%	33%	17%	31%	4%	0%
Cuba	412	3%	12%	8%	49%	28%	0%
Czech Republic	895	6%	13%	7%	30%	22%	22%
Dominican Republic	396	4%	16%	11%	32%	7%	30%
Egypt	5,031	8%	42%	11%	36%	3%	0%
Eritrea	57	5%	25%	19%	46%	2%	4%
Estonia	106	7%	8%	5%	60%	19%	1%
Ethiopia	157	6%	40%	17%	36%	1%	0%
Finland	168	6%	27%	13%	38%	16%	0%
France	6,727	7%	15%	10%	40%	28%	0%
Georgia	272	4%	20%	7%	47%	22%	0%
Ghana	306	11%	47%	23%	13%	0%	7%
Greece	839	4%	9%	6%	48%	33%	0%
Guatemala	255	4%	17%	15%	46%	8%	9%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Guyana	16	6%	38%	0%	50%	6%	0%
Honduras	314	7%	25%	14%	46%	3%	6%
Hungary	871	2%	9%	5%	37%	46%	0%
India	19,690	2%	14%	11%	41%	9%	23%
Indonesia	2,214	8%	32%	18%	37%	3%	1%
Iran	5,271	4%	13%	8%	56%	20%	0%
Iraq	1,908	23%	40%	20%	15%	3%	0%
Ireland	664	4%	18%	9%	37%	32%	0%
Israel	618	10%	17%	9%	40%	24%	0%
Jamaica	56	4%	16%	11%	41%	21%	7%
Kenya	528	13%	30%	27%	14%	13%	4%
Korea, Republic of	1,746	4%	11%	6%	54%	24%	0%
Kuwait	30	23%	27%	20%	0%	0%	30%
Lebanon	175	9%	16%	10%	46%	18%	1%
Lesotho	20	5%	10%	65%	20%	0%	0%
Lithuania	156	0%	0%	0%	0%	0%	100%
Madagascar	73	12%	30%	19%	33%	5%	0%
Malawi	38	8%	34%	11%	24%	0%	24%
Malaysia	950	11%	18%	10%	42%	10%	9%
Maldives	14	7%	21%	21%	29%	21%	0%
Mali	132	17%	48%	18%	13%	1%	2%
Mauritania	64	13%	48%	14%	20%	5%	0%
Mauritius	76	0%	8%	12%	45%	32%	4%
Mexico	4,809	1%	13%	12%	47%	15%	12%
Mongolia	81	16%	43%	9%	28%	4%	0%
Montenegro	42	5%	12%	12%	33%	38%	0%
Morocco	722	13%	19%	10%	38%	4%	17%
Mozambique	98	5%	27%	6%	60%	2%	0%
Myanmar	587	21%	35%	12%	23%	3%	5%
Nepal	571	9%	20%	15%	43%	8%	5%
Netherlands	1,115	5%	10%	7%	34%	43%	0%
New Zealand	478	0%	0%	0%	0%	0%	100%
Nicaragua	295	8%	28%	17%	44%	2%	0%
Nigeria	413	3%	29%	28%	19%	2%	19%
Norway	343	8%	16%	9%	36%	30%	0%
Pakistan	1,890	3%	30%	18%	45%	3%	0%
Panama	277	4%	17%	10%	50%	19%	0%
Paraguay	395	9%	11%	20%	33%	27%	0%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Philippines	1,155	3%	13%	12%	51%	8%	13%
Poland	2,562	0%	0%	0%	0%	0%	100%
Portugal	744	4%	5%	7%	27%	22%	35%
Qatar	49	10%	24%	29%	35%	2%	0%
Saudi Arabia	511	22%	37%	18%	23%	0%	0%
Senegal	241	10%	38%	15%	34%	4%	0%
Serbia	468	5%	12%	5%	47%	30%	0%
Singapore	226	8%	8%	5%	41%	37%	0%
Slovak Republic	529	3%	10%	6%	44%	37%	0%
Slovenia	220	6%	8%	4%	37%	45%	0%
South Africa	1,967	3%	15%	10%	43%	28%	2%
Sri Lanka	883	18%	17%	7%	23%	5%	30%
Sudan	1,036	21%	34%	14%	26%	3%	0%
Suriname	15	13%	20%	0%	47%	20%	0%
Syria	813	15%	27%	17%	34%	5%	2%
Tajikistan	521	8%	28%	14%	45%	5%	0%
Thailand	1,557	22%	40%	10%	20%	9%	0%
Togo	34	3%	50%	6%	32%	6%	3%
Trinidad and Tobago	60	0%	0%	0%	100%	0%	0%
Uganda	235	31%	40%	9%	15%	3%	0%
United Kingdom	6,860	6%	13%	7%	39%	36%	0%
United States	13,915	9%	24%	12%	34%	21%	0%
Uruguay	209	3%	15%	9%	34%	26%	12%
Uzbekistan	1,437	5%	23%	8%	54%	9%	0%
Venezuela	2,275	5%	13%	9%	39%	17%	17%
Vietnam	3,248	4%	20%	11%	51%	11%	3%
Zambia	129	18%	24%	15%	11%	3%	29%
Zimbabwe	159	3%	21%	11%	51%	6%	8%

TABLE 12. **Age distribution: Hemophilia B**

(99 countries reported age data for hemophilia B)

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	44	2%	41%	32%	25%	0%	0%
Albania	33	6%	9%	0%	64%	21%	0%
Argentina	378	3%	17%	11%	48%	19%	3%
Armenia	22	18%	14%	5%	32%	32%	0%
Australia	519	4%	12%	8%	38%	38%	0%
Austria	138	1%	12%	7%	45%	36%	0%
Bahamas	1	0%	0%	0%	100%	0%	0%
Bangladesh	339	17%	34%	19%	26%	3%	0%
Barbados	13	8%	8%	15%	54%	15%	0%
Belgium	243	2%	9%	7%	34%	48%	0%
Belize	5	0%	0%	20%	80%	0%	0%
Bolivia	34	15%	35%	0%	50%	0%	0%
Botswana	8	13%	50%	0%	38%	0%	0%
Brazil	2,139	5%	15%	10%	50%	21%	0%
Burkina Faso	25	20%	32%	24%	20%	0%	4%
Cambodia	33	9%	39%	21%	21%	9%	0%
Cameroon	28	29%	18%	43%	11%	0%	0%
Canada	683	2%	11%	7%	41%	39%	0%
Chile	170	8%	16%	11%	49%	17%	0%
Colombia	630	4%	13%	7%	64%	12%	0%
Costa Rica	36	6%	17%	6%	58%	14%	0%
Cote d'Ivoire	17	18%	47%	18%	12%	6%	0%
Cuba	78	4%	13%	5%	45%	33%	0%
Czech Republic	138	5%	14%	9%	20%	28%	24%
Dominican Republic	48	2%	8%	2%	56%	4%	27%
Egypt	1,166	6%	40%	14%	38%	3%	0%
Eritrea	7	14%	43%	0%	43%	0%	0%
Estonia	11	9%	27%	9%	27%	27%	0%
Ethiopia	30	10%	23%	13%	50%	3%	0%
Finland	31	3%	19%	16%	42%	19%	0%
France	1,603	7%	16%	11%	36%	29%	0%
Georgia	54	7%	20%	2%	44%	26%	0%
Ghana	25	12%	32%	20%	8%	0%	28%
Greece	186	2%	10%	4%	41%	43%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Guatemala	65	18%	22%	26%	15%	2%	17%
Guyana	1	0%	100%	0%	0%	0%	0%
Honduras	35	9%	26%	20%	40%	3%	3%
Hungary	237	3%	5%	4%	42%	46%	0%
India	3,150	2%	13%	11%	44%	11%	18%
Indonesia	347	10%	34%	22%	29%	2%	3%
Iran	1,118	4%	11%	8%	58%	20%	0%
Iraq	508	23%	40%	20%	13%	5%	0%
Ireland	251	4%	14%	11%	42%	29%	0%
Israel	106	15%	16%	14%	37%	18%	0%
Jamaica	4	0%	0%	0%	75%	25%	0%
Kenya	122	20%	25%	30%	20%	3%	2%
Korea, Republic of	434	3%	15%	10%	50%	23%	0%
Kuwait	6	17%	33%	0%	0%	0%	50%
Lebanon	48	4%	17%	21%	50%	8%	0%
Lithuania	26	0%	0%	0%	0%	0%	100%
Madagascar	60	17%	43%	12%	27%	2%	0%
Malawi	8	0%	38%	0%	13%	0%	50%
Malaysia	177	8%	16%	14%	42%	13%	6%
Maldives	4	25%	50%	25%	0%	0%	0%
Mali	12	58%	25%	8%	8%	0%	0%
Mauritania	17	12%	47%	12%	24%	6%	0%
Mauritius	11	9%	9%	9%	64%	9%	0%
Mexico	730	2%	14%	10%	50%	14%	10%
Mongolia	29	14%	38%	10%	31%	7%	0%
Montenegro	4	0%	0%	25%	50%	25%	0%
Morocco	146	14%	19%	14%	42%	3%	6%
Mozambique	2	0%	50%	50%	0%	0%	0%
Myanmar	99	41%	27%	7%	15%	4%	5%
Nepal	104	6%	28%	13%	34%	12%	8%
Netherlands	162	4%	9%	12%	35%	40%	0%
New Zealand	112	0%	0%	0%	0%	0%	100%
Nicaragua	55	7%	11%	16%	29%	2%	35%
Nigeria	14	14%	50%	14%	0%	0%	21%
Norway	92	4%	17%	12%	34%	33%	0%
Pakistan	343	6%	22%	13%	55%	4%	0%
Panama	37	8%	16%	14%	49%	14%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Paraguay	39	5%	18%	23%	28%	26%	0%
Philippines	201	5%	14%	9%	55%	6%	9%
Poland	464	0%	0%	0%	0%	0%	100%
Portugal	201	4%	6%	6%	27%	25%	31%
Qatar	8	25%	13%	25%	38%	0%	0%
Saudi Arabia	126	16%	41%	9%	34%	0%	0%
Senegal	33	15%	52%	21%	9%	3%	0%
Serbia	88	3%	17%	10%	47%	23%	0%
Singapore	43	2%	14%	9%	56%	19%	0%
Slovak Republic	82	9%	15%	10%	46%	21%	0%
Slovenia	31	3%	13%	3%	39%	42%	0%
South Africa	378	2%	19%	10%	41%	27%	1%
Sri Lanka	212	18%	20%	8%	4%	5%	45%
Sudan	249	18%	41%	16%	23%	2%	0%
Syria	93	13%	29%	20%	34%	1%	2%
Tajikistan	59	5%	20%	24%	15%	36%	0%
Thailand	206	35%	30%	12%	14%	9%	0%
Togo	8	0%	25%	25%	13%	0%	38%
Trinidad and Tobago	12	0%	0%	0%	100%	0%	0%
Uganda	36	22%	42%	17%	19%	0%	0%
United Kingdom	1,537	5%	15%	6%	39%	35%	0%
United States	4,093	9%	23%	12%	29%	28%	0%
Uruguay	41	7%	22%	5%	49%	12%	5%
Uzbekistan	164	10%	26%	7%	48%	10%	0%
Venezuela	598	3%	13%	7%	40%	21%	17%
Vietnam	692	5%	20%	11%	50%	12%	2%
Zambia	28	39%	11%	32%	18%	0%	0%
Zimbabwe	14	0%	29%	43%	29%	0%	0%

TABLE 13. **Age distribution: Hemophilia Type Unknown**

(30 countries reported age data)

	Hemophilia type unknown	0–4	5–13	14–18	19–44	45+	Age not known
Armenia	19	0%	5%	21%	47%	26%	0%
Bahamas	1	0%	100%	0%	0%	0%	0%
Bangladesh	6	0%	0%	100%	0%	0%	0%
Belgium	9	0%	0%	0%	11%	78%	11%
Bolivia	3	0%	0%	0%	0%	0%	100%
Cameroon	7	43%	29%	29%	0%	0%	0%
Chile	77	0%	0%	0%	0%	0%	100%
Dominican Republic	31	0%	26%	3%	45%	10%	16%
Ethiopia	145	12%	40%	21%	27%	0%	0%
Finland	54	0%	0%	0%	56%	44%	0%
Ghana	10	100%	0%	0%	0%	0%	0%
Guatemala	51	2%	6%	2%	2%	0%	88%
Honduras	27	4%	26%	11%	19%	4%	37%
India	826	2%	6%	6%	24%	6%	57%
Indonesia	123	4%	35%	7%	41%	3%	10%
Iran	3,641	6%	20%	10%	51%	14%	0%
Lithuania	1	0%	0%	0%	0%	0%	100%
Malawi	24	17%	38%	8%	33%	0%	4%
Mali	10	20%	60%	10%	0%	10%	0%
Mexico	314	1%	4%	7%	25%	11%	52%
Myanmar	7	29%	71%	0%	0%	0%	0%
Nigeria	38	5%	8%	11%	0%	0%	76%
Philippines	210	1%	9%	12%	46%	6%	26%
Syria	4	50%	25%	25%	0%	0%	0%
Tajikistan	1	0%	100%	0%	0%	0%	0%
Togo	5	0%	40%	20%	20%	0%	20%
Uganda	2	50%	0%	50%	0%	0%	0%
Uruguay	7	0%	0%	43%	43%	0%	14%
Uzbekistan	10	0%	0%	100%	0%	0%	0%
Zambia	32	16%	0%	19%	66%	0%	0%

TABLE 14. **Age distribution: VWD**

(81 countries reported age data)

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	2	0%	100%	0%	0%	0%	0%
Albania	6	0%	17%	0%	83%	0%	0%
Argentina	397	0%	1%	2%	43%	40%	14%
Australia	2,221	1%	9%	6%	44%	40%	0%
Bahamas	2	0%	0%	0%	100%	0%	0%
Bangladesh	4	25%	50%	0%	25%	0%	0%
Belgium	2,106	1%	13%	10%	41%	34%	1%
Bolivia	3	0%	33%	0%	33%	33%	0%
Botswana	6	0%	67%	33%	0%	0%	0%
Brazil	9,462	1%	10%	9%	53%	27%	0%
Cambodia	6	17%	50%	33%	0%	0%	0%
Cameroon	4	0%	0%	100%	0%	0%	0%
Canada	4,522	1%	7%	7%	48%	37%	0%
Chile	492	0%	0%	0%	0%	0%	100%
Colombia	3,391	4%	12%	18%	54%	11%	1%
Costa Rica	94	0%	2%	9%	48%	39%	2%
Cote d'Ivoire	3	0%	33%	0%	33%	33%	0%
Cuba	398	1%	11%	24%	43%	21%	0%
Czech Republic	761	1%	8%	7%	34%	30%	20%
Dominican Republic	42	5%	7%	10%	57%	10%	12%
Egypt	597	6%	47%	13%	31%	4%	0%
Estonia	118	2%	19%	9%	46%	16%	8%
Finland	553	0%	6%	8%	50%	35%	0%
France	2,742	5%	14%	12%	38%	32%	0%
Georgia	43	5%	19%	19%	33%	26%	0%
Ghana	9	0%	100%	0%	0%	0%	0%
Guatemala	22	0%	14%	14%	27%	18%	27%
Honduras	19	11%	26%	16%	37%	0%	11%
Hungary	1,378	1%	7%	6%	37%	48%	0%
India	760	2%	16%	13%	46%	8%	13%
Indonesia	22	9%	23%	18%	36%	9%	5%
Iran	1,678	4%	17%	11%	53%	15%	0%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Iraq	507	19%	29%	37%	11%	3%	0%
Ireland	1,644	4%	20%	7%	42%	27%	0%
Jamaica	3	0%	0%	0%	0%	100%	0%
Kenya	33	15%	33%	33%	15%	3%	0%
Korea, Republic of	146	2%	9%	10%	54%	25%	0%
Kuwait	5	40%	20%	0%	0%	0%	40%
Lebanon	163	4%	20%	7%	54%	11%	4%
Lithuania	306	0%	0%	0%	0%	0%	100%
Madagascar	2	0%	0%	0%	0%	100%	0%
Malaysia	141	1%	10%	8%	61%	6%	14%
Mali	19	21%	21%	21%	32%	5%	0%
Mauritania	1	0%	100%	0%	0%	0%	0%
Mauritius	1	0%	100%	0%	0%	0%	0%
Mexico	339	0%	11%	10%	42%	14%	24%
Mongolia	14	0%	14%	29%	43%	14%	0%
Montenegro	3	0%	0%	33%	67%	0%	0%
Morocco	157	9%	10%	17%	63%	1%	0%
Myanmar	23	17%	48%	9%	4%	0%	22%
Nepal	9	22%	22%	22%	22%	0%	11%
Netherlands	346	2%	19%	9%	30%	40%	0%
New Zealand	95	0%	0%	0%	0%	0%	100%
Nicaragua	91	4%	16%	18%	51%	8%	3%
Nigeria	12	0%	25%	17%	8%	0%	50%
Pakistan	340	6%	30%	14%	48%	2%	0%
Panama	515	0%	15%	19%	54%	12%	0%
Philippines	46	0%	4%	11%	30%	7%	48%
Poland	2,200	0%	0%	0%	0%	0%	100%
Portugal	853	0%	1%	1%	8%	7%	83%
Qatar	42	7%	29%	33%	31%	0%	0%
Saudi Arabia	241	17%	34%	24%	24%	0%	0%
Senegal	10	10%	30%	40%	10%	10%	0%
Serbia	313	2%	9%	4%	51%	34%	0%
Singapore	95	0%	13%	4%	37%	46%	0%
Slovak Republic	733	1%	6%	4%	54%	35%	0%
Slovenia	189	2%	5%	8%	53%	31%	0%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
South Africa	654	0%	4%	6%	42%	43%	4%
Sri Lanka	63	14%	27%	3%	8%	10%	38%
Sudan	333	19%	36%	17%	24%	3%	0%
Suriname	3	0%	0%	33%	33%	33%	0%
Syria	116	14%	29%	13%	38%	6%	0%
Tajikistan	40	0%	8%	10%	83%	0%	0%
Uganda	3	0%	33%	33%	0%	33%	0%
United Kingdom	11,066	3%	11%	6%	41%	40%	0%
United States	12,394	6%	31%	23%	24%	17%	0%
Uruguay	263	0%	1%	1%	1%	1%	95%
Uzbekistan	158	4%	32%	14%	40%	10%	0%
Venezuela	1,177	1%	13%	11%	39%	17%	18%
Vietnam	181	4%	26%	12%	41%	13%	3%
Zambia	5	0%	0%	80%	0%	20%	0%

TABLE 15. **HIV and HCV infection**

(82 countries reported HIV and/or HCV data)

Please note: the number of people infected with HCV does not refer to the number of people with active HCV.

Data on HIV and HCV are based on a small number of countries and do not reflect the true global burden of these infections in the bleeding disorders community.

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Afghanistan				2					
Albania	1	0	0	35	0	0	0	0	0
Algeria	2	0	0	19	3	2	4	2	0
Argentina	55			600	20				
Armenia		1		62			2		
Austria	44			195					
Bahamas	0	0	0	0	0	0	0	0	0
Barbados	0			2			0		
Belarus	0	0	0	86	12				
Botswana	3	0	0						
Cameroon	0	0	0	0	0	0	0	0	0
Chile	2	0	0						
Colombia	10	2	0	192	50	0	81	0	0
Costa Rica	11	0	0	48	0	0			
Cote d'Ivoire	1	0	0	0	0	0	0	0	0
Cuba	3	0	0	133	16	2	130	16	2
Czech Republic	3	0	0	187	4	1	24	1	0
Dominican Republic	0	0	0	27	0	8	20	0	8
Eritrea	0	0	0						
Estonia	1	0	0	28	1				
France	539	18	5	2099	181	50	36	1	0
Georgia				19	2				
Germany	365								
Ghana	0	0	0	0	0	0	0	0	0
Greece	49	2	0	283	22	7	12	1	0
Guatemala							2		
Guyana	0	0	0	0	0	0	0	0	0

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Honduras	0	1	0						
Hungary	10			371	111				
India	77	62	2	159	4	1	30	2	4
Indonesia	2								
Iran	24	1	1	1069	155	152	100	15	15
Iraq	1			300	65	9		1	
Ireland	33	0	0	134	7	2	3	0	0
Israel	23	0							
Jamaica	1	0	0	2	0	0	2	0	0
Japan	708	9	3	1791	95	57			
Jordan	0								
Kenya	23	2	0	2	0	0	0	0	0
Korea, Republic of	18	0	0	557	2	6	71	0	1
Kuwait	0	0		0	0	0	0	0	0
Lebanon	0	0	0	1	0	0	0	0	0
Madagascar	0	0	0	1	0	0	0	0	0
Malawi	0			0			0		
Malaysia	3	0	0	33	2	0	18	2	0
Mali	0	0	0	0	0	0	0	0	0
Mauritius	0	0	0	8	0	1	0	0	0
Mexico	43	3	0	269	6	0			
Montenegro	0	0	0	3	0	0	1	0	0
Morocco				80	1		7		
Mozambique	4	0	0	1	0	0	0	0	0
Myanmar	1	0	0	12	0	0	0	0	0
Nepal	0			9					
Nicaragua	0	0	0	34	0	0	24	0	0
Norway	6	0	0						
Pakistan	8	0	0	105	34	9	59	9	1
Panama	0	0	0	0	0	0	0	0	0
Paraguay	0	0	0	0	0	0	0	0	0
Poland	3	0	0						
Qatar	0	0	0	0	0	0	0	0	0
Saudi Arabia	0			0			0		

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Senegal	0	0	0	0	1	0	0	0	0
Serbia	7	2	0	115	12	2			
Singapore	0	0	0	69	2	0	6	0	0
Slovak Republic	0	0	0	120	18	14	16	2	0
Slovenia	7	0	0	96	6	0	0	0	0
Sri Lanka				1			0		
Sudan	1	1	1	43					
Suriname	0	0	0	0	0	0	0	0	0
Sweden	29	0	0						
Syria				71	6				
Tajikistan	0	0	0	0	0	0	0	0	0
Thailand	12	0		68	1		3		
Tunisia	10			76			2		
Uganda	1	1							
United Kingdom	263	4	0	1567	167	26			
United States	945	45	31				1683	103	75
Uruguay	0	0	0	6	0	0	6	0	0
Uzbekistan	8	0		190	10				
Venezuela	80	9		80	9		258	18	
Vietnam	5	0	0	352	2	46	352	0	0
Zambia	1	0	0	0	0	0	0	0	0

** Hepatitis C antibody positive at any time*

*** Still PCR positive: patients who have not cleared the virus spontaneously or after treatment*

TABLE 16. **Percentage of patients on prophylaxis**

(95 countries reported prophylaxis data)

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Afghanistan	2	Estimate		
Algeria	90	Estimate	35	Estimate
Argentina	80	Estimate	15	Estimate
Armenia	50	Estimate	25	Estimate
Australia	92	Estimate	76	Estimate
Austria	88	Precise	74	Precise
Bahamas	0	Precise	0	Precise
Barbados	6	Estimate	1	Estimate
Belarus	100	Estimate	2	Estimate
Belgium	90	Estimate	75	Estimate
Bolivia	50	Estimate		
Bosnia-Herzegovina	90	Estimate		
Botswana	100	Precise	80	Estimate
Brazil	87	Precise	64	Precise
Cambodia	2	Estimate	1	Estimate
Cameroon	0	Precise	0	Precise
Canada	91	Estimate	82	Estimate
Chile	100	Estimate	50	Estimate
Colombia	97	Precise	85	Precise
Costa Rica	50	Precise	50	Precise
Cote d'Ivoire	34	Precise	0	Precise
Cuba	12	Precise		
Czech Republic	87	Precise	68	Precise
Dominican Republic	35	Precise	0	Precise
Egypt	5	Estimate	1	Estimate
Eritrea	90	Estimate	0	Precise
Estonia	88	Precise	20	Precise
Ethiopia	0	Precise	0	Precise
Finland	80	Estimate		
France	80	Precise	62	Precise
Georgia	30	Estimate		
Germany	100	Estimate		
Ghana	60	Estimate	50	Estimate
Greece	93	Precise	61	Precise

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Guatemala	17	Precise	1	Precise
Guyana	80	Precise	100	Precise
Hungary	100	Precise	70	Estimate
India	9	Precise	4	Estimate
Indonesia	0	Precise	0	Precise
Iran	45	Precise	25	Precise
Iraq	100	Precise	10	Precise
Ireland	96	Estimate	95	Estimate
Israel	95	Precise	72	Precise
Jamaica	0	Precise	0	Precise
Japan	10	Estimate	14	Estimate
Jordan	10	Estimate	10	Estimate
Kenya	0	Precise	0	Precise
Korea, Republic of	75	Precise	60	Precise
Kuwait	90	Estimate		
Latvia			100	Precise
Lebanon	32	Estimate	15	Estimate
Lesotho	0	Estimate	0	Estimate
Lithuania	100	Precise	60	Precise
Madagascar	10	Estimate	10	Estimate
Malawi	29	Estimate	24	Estimate
Malaysia	85	Estimate	80	Estimate
Maldives	1	Estimate		
Mali	95	Estimate	10	Estimate
Mauritius	100	Precise	100	Precise
Montenegro	89	Precise	67	Precise
Morocco	25	Estimate	10	Estimate
Mozambique	20	Estimate	30	Estimate
Netherlands			90	Estimate
New Zealand	97	Estimate	71	Estimate
Nicaragua	0	Precise	0	Precise
Nigeria	98	Estimate	0	Precise
Norway	95	Estimate	80	Estimate
Pakistan	60	Precise	0	Precise
Palestine	65	Estimate	25	Estimate
Panama	100	Estimate		
Philippines	1	Estimate	0	Estimate
Poland	80	Estimate	60	Estimate

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Qatar	80	Precise	80	Precise
Romania	100	Precise	40	Precise
Russia	90	Estimate	65	Estimate
Saudi Arabia	30	Estimate	50	Estimate
Senegal	19	Precise	0	Precise
Serbia	90	Precise	35	Precise
Singapore	92	Precise	58	Precise
Slovak Republic	96	Precise	63	Precise
Slovenia	100	Precise	78	Precise
South Africa	40	Estimate	25	Estimate
Suriname	20	Precise	0	Precise
Sweden	95	Estimate	90	Estimate
Thailand	30	Estimate	10	Estimate
Togo	0	Estimate	0	Estimate
Tunisia	78	Precise	53	Precise
Uganda	1	Precise	1	Precise
Ukraine	50	Precise	10	Precise
United Kingdom	92	Estimate	87	Estimate
Uruguay	100	Estimate	10	Estimate
Uzbekistan	5	Precise	0	Precise
Venezuela	35	Precise	10	Precise
Vietnam	11	Estimate	1	Estimate
Zambia	29	Precise	29	Precise

TABLE 17. **Use of Factor Concentrates in 2019: Factor VIII**

(101 countries reported Factor VIII data)

The quantities of factor VIII in this chart are as reported to the WFH and are not independently verified except when the WFH provided humanitarian aid products. In some cases the numbers reported may be based on an estimate or from one region or certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2019 while others report the amount purchased. Factor VIII IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. The per capita number divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients. Please note that some FVIII products are used in the treatment of von Willebrand disease and not for hemophilia A.

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Afghanistan	1,196,000	No data	No data	No data				1,196,000	1,196,000	0	0.031	0
Albania	6,500,000	3,400,000	100,000	0	97	3	0	3,000,000			2.277	1.226
Algeria	96,071,250	57,492,500	38,578,750	No data	60	40		0			2.231	2.231
Argentina	193,758,250	107,989,000	84,705,000	No data	56	44		1,064,250	1,064,250	0	4.312	4.288
Armenia	2,473,500	500,000	No data	No data	100			1,973,500	1,598,500	375,000	0.836	0.169
Australia	193,931,300	21,590,250	137,879,300	34,461,750	11	71	18	0			7.646	7.646
Bahamas	187,000	0	0	27,000	0	0	100	160,000	137,500	0	0.48	0.069
Bangladesh	7,852,000	No data	No data	No data				7,852,000	5,377,000	2,200,000	0.048	0
Barbados	300,000	No data	No data	No data				300,000	300,000	0	1.045	0
Belarus	30,000,000	30,000,000	No data	No data	100			No data			3.169	3.169
Belize	641,318	No data	No data	No data				641,318	290,000	49,000	1.643	
Bolivia	2,187,000	392,500	No data	No data	100			1,794,500	200,000	1,202,000	0.19	0.034
Brazil	909,376,000	226,973,000	682,403,000	No data	25	75		0			4.309	4.309
Burkina Faso	600,000	No data	No data	No data				600,000	450,000	150,000	0.03	0
Cambodia	3,091,500	No data	No data	No data				3,091,500	2,304,000	787,500	0.188	0
Cameroon	1,137,500	No data	No data	No data				1,137,500	950,000	187,500	0.044	0
Canada	329,806,823	45,738,359	214,946,234	69,122,230	14	65	21	0			8.774	8.774
Chile	78,000,000	78,000,000	0	0	100	0	0	0			4.116	4.116
Colombia	247,203,000	62,832,000	172,564,000	11,795,000	25	70	5	12,000			4.911	4.91
Costa Rica	16,492,250	16,492,250	0	0	100	0	0	0			3.267	3.267

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Cote d'Ivoire	612,500	0	0	0	0	0	0	612,500			0.024	0
Cuba	5,655,750	5,090,000	0	0	100	0	0	565,750	446,750	0	0.499	0.449
Czech Republic	57,595,609	12,560,842	38,804,367	6,230,400	22	67	11	0			5.398	5.398
Dominican Republic	3,808,500	No data	No data	No data				3,808,500	1,916,000	1,892,500	0.355	0
Egypt	48,819,500	27,160,000	13,860,000	0	66	34	0	7,799,500			0.486	0.409
Eritrea	542,000	0	0	0	0	0	0	542,000	542,000	0	0.092	0
Estonia	8,005,250	5,630,750	2,298,500	76,000	70	29	1	0			6.034	6.034
Ethiopia	2,492,750	0	0	0	0	0	0	2,492,750	2,042,750	450,000	0.022	0
Finland	43,473,050	3,143,800	23,435,250	16,894,000	7	54	39	No data			7.875	7.875
France	500,250,250	41,613,500	240,531,750	218,105,000	8	48	44	No data			7.46	7.46
Georgia	13,000,000	13,000,000	0	0	100	0	0	0			3.494	3.494
Germany	643,887,955	205,858,055	438,029,900	No data	32	68		0			7.745	7.745
Ghana	3,382,250	No data	No data	No data				3,382,250	2,707,250	675,000	0.111	0
Greece	55,824,624	5,327,124	36,867,750	13,629,750	10	66	24	0			5.209	5.209
Guatemala	5,946,126	No data	No data	No data				106,626			0.358	0.352
Guyana	612,500	No data	No data	No data				612,500	612,500	0	0.782	0
Honduras	10,353,500	7,003,500	0	0	100	0	0	3,350,000	2,200,000	1,150,000	1.062	0.719
Hungary	128,406,000	57,750,000	70,656,000	No data	45	55		No data			13.143	13.143
India	395,397,750	145,000,000	210,000,000	No data	41	59		40,397,750	15,111,500	16,864,250	0.289	0.26
Indonesia	3,000,000	No data	No data	No data				3,000,000	3,000,000	0	0.011	0
Iran	182,608,250	102,168,000	75,440,250	No data	56	41		No data			2.202	2.202
Iraq	35,000,000	0	35,000,000	0	0	100	0	0			0.89	0.89
Ireland	54,856,900	2,376,150	565,000	51,915,750	4	1	95	0			11.101	11.101
Jamaica	513,000	0	0	0	0	0	0	513,000	413,000	100,000	0.174	0
Jordan	10,687,500	5,840,000	1,460,000	0	80	20	0	3,387,500	1,100,000	2,287,500	1.058	0.723
Kenya	5,611,250	0	0	0	0	0	0	5,611,250	2,686,250	2,925,000	0.107	0
Korea, Republic of	296,247,000	55,844,000	240,403,000	No data	19	81		No data			5.729	5.729
Latvia	8,649,250	986,000	7,663,250	0	11	89	0	0			4.522	4.522
Lebanon	14,302,000	7,400,000	5,920,000	0	56	44	0	982,000	982,000	0	2.086	1.943
Lithuania	28,149,500	10,562,000	17,491,500	96,000	38	62	0	No data			10.101	10.101

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Madagascar	1,725,000	No data	No data	No data				1,725,000	1,400,000	325,000	0.064	0
Malawi	400,000	No data	No data	No data				400,000	300,000	100,000	0.021	0
Malaysia	46,594,250	43,601,500	2,992,750	0	94	6	0	0			1.458	1.458
Maldives	450,000	No data	No data	No data				450,000	450,000	0	0.848	0
Mali	1,375,000	0	0	0	0	0	0	1,375,000	850,000	525,000	0.07	0
Mauritania	915,000	269,000	0	0	100	0	0	646,000	546,000	100,000	0.202	0.059
Mauritius	6,388,000	6,025,000	0	0	100	0	0	363,000	363,000	0	5.047	4.76
Mexico	223,407,906	103,790,502	118,987,404	0	47	53	0	630,000			1.751	1.746
Mongolia	4,626,000	0	709,500	No data	0	100		3,916,500	3,566,500	350,000	1.434	0.22
Montenegro	1,650,000	1,650,000	No data	No data	100			No data			2.652	2.652
Morocco	30,761,700	17,538,000	9,373,700	No data	65	35		3,850,000	3,100,000	750,000	0.843	0.738
Mozambique	995,300	210,000	0	0	100	0	0	785,300			0.033	0.007
Myanmar	5,172,500	No data	No data	No data				5,172,500	3,972,500	1,200,000	0.096	0
Nepal	3,164,500	No data	No data	No data				3,164,500	2,727,000	437,500	0.111	0
New Zealand	27,539,750	2,935,000	15,930,250	8,674,500	11	58	31	No data			5.601	5.601
Nicaragua	2,874,000	0	0	0	0	0	0	2,874,000	1,150,000	1,724,000	0.439	0
Nigeria	5,221,500	0	0	0	0	0	0	5,221,500	4,471,500	750,000	0.026	0
Pakistan	8,649,750	418,000	0	0	100	0	0	8,231,750	5,319,250	2,912,500	0.04	0.002
Palestine	1,500,000	No data	No data	No data				1,500,000	1,500,000	0	0.32	0
Panama	6,555,250	6,351,500	203,750	0	97	3	0	No data			1.544	1.544
Paraguay	2,379,500	811,500	No data	No data	100			1,568,000	300,000	1,268,000	0.338	0.115
Philippines	11,114,500	1,825,500	0	0	100	0	0	9,289,000	7,289,000	2,000,000	0.103	0.017
Poland	308,721,750	288,297,250	20,424,500	0	93	7	0	0			8.13	8.13
Portugal	56,985,500	14,020,000	36,007,500	6,958,000	25	63	12	No data			5.549	5.549
Qatar	16,800,000	0	13,800,000	3,000,000	0	82	18	0			5.932	5.932
Romania	71,764,200	48,831,450	22,932,750	0	68	32	0	0			3.707	3.707
Russia	965,773,000	538,173,500	427,599,500	0	56	44	0	0			6.689	6.689
Saudi Arabia	92,575,000	36,225,000	41,350,000	15,000,000	39	45	16	0			2.701	2.701
Senegal	1,715,500	35,000	0	0	100	0	0	1,680,500	1,230,500	450,000	0.105	0.002
Serbia	25,388,750	10,000,000	15,388,750	0	39	61	0	0			3.656	3.656
Singapore	12,656,750	4,173,000	8,483,750	0	33	67	0	0			2.219	2.219

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Slovak Republic	45,800,000	30,500,000	12,200,000	3,100,000	67	27	7	0			8.397	8.397
Slovenia	16,566,500	525,000	10,391,500	5,650,000	3	63	34	0			7.934	7.934
South Africa	71,500,000	68,800,000	2,700,000	0	96	4	0	0			1.221	1.221
Sri Lanka	21,565,750	15,281,750	No data	No data	100			6,284,000	3,684,000	2,600,000	0.989	0.701
Sudan	10,710,000	10,710,000	No data	No data	100			No data			0.25	0.25
Sweden	101,310,250	573,000	70,427,250	30,310,000	1	70	30	0			9.85	9.85
Tanzania	944,000	No data	No data	No data				944,000	844,000	100,000	0.016	0
Thailand	43,315,100	16,826,040	25,239,060	No data	40	60		1,250,000	0	1,250,000	0.622	0.604
Togo	130,000	No data	No data	No data				130,000	130,000	0	0.016	0
Trinidad and Tobago	646,150	No data	No data	No data				646,150	550,000	0	0.463	0
Tunisia	16,428,750	9,428,750	7,000,000	0	57	43	0	0			1.405	1.405
Uganda	2,862,650	No data	No data	No data				2,862,650	1,900,000	762,500	0.065	0
United Kingdom	603,219,196	9,320,025	499,858,287	94,040,884	2	83	16	0			9.026	9.026
United States	2,332,000,000	157,000,000	1,567,000,000	608,000,000	7	67	26	No data			7.105	7.105
Uruguay	9,100,000	No data	0	0		0	0	0			2.629	2.629
Uzbekistan	15,505,000	913,000	0	0	100	0	0	14,592,000	6,429,000	1,350,000	0.462	0.027
Venezuela	40,883,250	No data	1,190,000	No data		100		39,693,250	32,149,250	6,521,000	1.434	0.042
Vietnam	27,656,500	26,306,500	0	0	100	0	0	1,350,000	0	1,350,000	0.287	0.273
Zambia	1,162,500	No data	No data	No data				1,162,500	775,000	387,500	0.065	0
Zimbabwe	2,362,500	No data	No data	No data				2,362,500	1,800,000	562,500	0.161	0
TOTAL	**9,998,003,157**	**2,837,078,347**	**5,719,793,002**	**1,197,086,264**				**224,106,044**	**134,423,750**	**59,070,750**		

TABLE 18. **Use of Factor Concentrates in 2019: Factor IX**

(93 countries reported Factor IX data.)

The quantities of factor IX in this chart are as reported to the WFH and are not independently verified except when the WFH provided humanitarian aid products. In some cases the numbers reported may be based on an estimate or from one region or certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2019 while others report the amount purchased. Factor IX Total IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. The factor IX per capita divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients.

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Afghanistan	919,000	No data	No data	No data				919000	0	0	0.02416	
Albania	500,000	500,000	0	0	100	0	0	0			0.17518	0.17518
Algeria	15,709,200	No data	No data	No data				0			0.36488	0.36488
Argentina	22,000,000	13,000,000	9,000,000	No data	59	41		No data	0	0	0.48956	0.48956
Armenia	350,000	0	No data	No data	0	0	0	350000	0	350000	0.11833	0
Australia	28,017,000	563,000	16,205,500	11,248,500	2	58	40	0			1.10458	1.10458
Bangladesh	850,000	No data	No data	No data				850000	0	500000	0.00521	
Belize	431,070	No data	No data	No data				431070	0	12500	1.10431	
Bolivia	336,000	80,500	No data	No data	100			255500	0	125000	0.02918	0.00699
Brazil	142,121,000	142,121,000	0	0	100	0	0	0			0.6734	0.6734
Burkina Faso	237,500	No data	No data	No data				237500	0	237500	0.01169	
Cambodia	87,000	No data	No data	No data				87000	0	87000	0.00528	
Cameroon	94,500	No data	No data	No data				94500	44500	50000	0.00365	
Canada	55,112,470	2,055,547	37,257,970	15,798,953	4	68	29	0			1.46618	1.46618
Chile	14,000,000	14,000,000	0	0	100	0	0	0			0.73871	0.73871
Colombia	35,853,000	14,456,000	20,777,000	620,000	40	58	2	0			0.71222	0.71222
Costa Rica	3,952,200	3,952,200	0	0	100	0	0	0			0.78299	0.78299
Cote d'Ivoire	50,000	0	0	0	0	0	0	50000			0.00194	0
Cuba	450,000	450,000	0	0	100	0	0	0	0	0	0.03971	0.03971
Czech Republic	8,015,571	2,173,171	4,871,400	971,000	27	61	12	0			0.75125	0.75125
Dominican Republic	403,000	No data	No data	No data				403000	30000	373000	0.03753	
Egypt	5,762,500	0	3,200,000	0	0	100	0	2562500			0.0574	0.03188

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Eritrea	7,250	0	0	0	0	0	0	7250	0	0	0.00124	0
Estonia	655,200	655,200	0	0	100	0	0	0			0.4939	0.4939
Ethiopia	312,500	0	0	0	0	0	0	312500	0	250000	0.00279	0
Finland	9,695,750	1,314,000	8,152,000	229,750	14	84	2	No data			1.75638	1.75638
France	82,805,500	5,785,000	22,184,250	54,836,250	7	27	66	No data			1.2348	1.2348
Georgia	1,200,000	1,200,000	0	0	100	0	0	0			0.32255	0.32255
Germany	63,501,407	21,906,707	41,594,700	No data	34	66		0			0.76386	0.76386
Ghana	283,000	No data	No data	No data				283000	108000	175000	0.0093	
Greece	6,025,500	46,500	2,914,500	3,064,500	1	48	51	0			0.56227	0.56227
Guatemala	1,666,500	No data	No data	No data				No data			0.10037	0.10037
Honduras	699,500	No data	No data	0				699500	0	699500	0.07177	
Hungary	8,000,000	8,000,000	0	0	100	0	0	No data			0.81884	0.81884
India	20,452,000	15,000,000	285,000	No data	98	2		5167000	0	5167000	0.01497	0.01119
Indonesia	108,000	No data	No data	No data				108000	108000	0	0.0004	
Iran	23,638,500	23,638,500	No data	No data	100			No data			0.2851	0.2851
Iraq	10,000,000	0	10,000,000	0	0	100	0	0			0.25439	0.25439
Ireland	10,797,750	No data	No data	10,799,750			100	0			2.18514	2.18514
Jamaica	62,500	0	0	0	0	0	0	62500	0	62500	0.0212	0
Jordan	2,070,750	1,700,000	0	0	100	0	0	370750	2000	368750	0.20499	0.16829
Kenya	600,000	0	0	0	0	0	0	600000	0	312500	0.01141	0
Korea, Republic of	71,619,000	3,183,000	68,436,000	No data	4	96		No data			1.38504	1.38504
Latvia	909,500	909,500	0	0	100	0	0	0			0.47548	0.47548
Lebanon	4,134,500	2,860,000	1,100,000	0	72	28	0	174500	0	0	0.60307	0.57762
Lithuania	10,472,000	10,472,000	0	0	100	0	0	No data			3.75766	3.75766
Madagascar	1,101,250	No data	No data	No data				1101250	0	995250	0.04083	
Malawi	67,000	No data	No data	No data				67000	0	62500	0.0036	
Malaysia	8,752,000	8,752,000	0	0	100	0	0	0			0.27393	0.27393
Maldives	50,000	No data	No data	No data				50000	0	50000	0.09417	
Mali	25,000	0	0	0	0	0	0	25000	0	25000	0.00127	0
Mauritania	206,000	143,500	0	0	100	0	0	62500	0	62500	0.04552	0.03171
Mauritius	350,000	350,000	0	0	100	0	0	0	0	0	0.27652	0.27652

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Mongolia	591,250	0	366,250	No data	0	100		225000	0	225000	0.18332	0.11356
Montenegro	275,000	275,000	No data	No data	100			No data			0.44202	0.44202
Morocco	1,833,500	568,000	635,500	No data	47	53		630000	30000	600000	0.05027	0.033
Mozambique	79,000	0	No data	No data	0	0	0	79000			0.0026	0
Myanmar	585,850	No data	No data	No data				585850	0	250000	0.01084	
Nepal	500,000	No data	No data	No data				500000	0	500000	0.01748	
New Zealand	5,348,250	99,000	4,048,750	1,200,500	2	76	22	No data			1.08771	1.08771
Nicaragua	500,000	0	0	0	0	0	0	500000	0	500000	0.07639	0
Nigeria	100,000	0	0	0	0	0	0	100000	0	100000	0.0005	0
Pakistan	1,571,250	162,500	0	0	100	0	0	1408750	0	962500	0.00726	0.00075
Panama	590,400	590,400	0	0	100	0	0	No data			0.13903	0.13903
Paraguay	709,000	156,000	No data	No data	100			553000	50000	503000	0.10064	0.02214
Philippines	600,000	0	0	0	0	0	0	600000	0	600000	0.00555	0
Poland	44,835,850	41,585,100	3,250,750	0	93	7	0	0			1.1808	1.1808
Portugal	7,809,500	3,875,000	3,848,500	86,000	50	49	1	No data			0.76046	0.76046
Qatar	4,500,000	4,500,000	0	0	100	0	0	0			1.58895	1.58895
Romania	7,551,450	No data	No data	No data				0			0.39012	0.39012
Russia	96,392,250	73,071,250	23,321,000	0	76	24	0	0			0.66766	0.66766
Saudi Arabia	12,000,000	7,000,000	4,000,000	1,000,000	58	33	8	0			0.35018	0.35018
Senegal	175,000	0	0	0	0	0	0	175000	0	62500	0.01074	0
Serbia	3,535,000	975,000	2,560,000	0	28	72	0	No data			0.509	0.509
Singapore	2,281,000	211,500	2,019,500	50,000	9	89	2	0			0.39993	0.39993
Slovak Republic	4,681,000	3,281,000	300,000	1,100,000	70	6	23	0			0.85826	0.85826
Slovenia	1,766,500	67,000	1,546,500	153,000	4	88	9	0			0.84605	0.84605
South Africa	11,000,000	11,000,000	0	0	100	0	0	0			0.18785	0.18785
Sri Lanka	2,618,000	2,268,000	No data	No data	100			350000	0	350000	0.12008	0.10402
Sudan	1,487,000	1,487,000	No data	No data	100			No data			0.03473	0.03473
Sweden	17,942,900	3,964,400	7,307,500	6,671,000	22	41	37	0			1.74449	1.74449
Tanzania	125,000	No data	No data	No data				125000	0	125000	0.00215	
Thailand	4,168,500	3,668,500	No data	No data	100			500000	0	500000	0.05987	0.05269
Tunisia	1,817,000	1,817,000	0	0	100	0	0	0			0.15537	0.15537
Uganda	200,000	No data	No data	No data				200000	0	200000	0.00452	

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
United Kingdom	76,036,548	2,384,495	41,063,050	32,589,003	3	54	43	0			1.13769	1.13769
United States	517,000,000	38,000,000	273,000,000	206,000,000	7	53	40	No data			1.57507	1.57507
Uruguay	600,000	No data	0	0		0	0	0			0.17332	0.17332
Uzbekistan	1,000,000	225,000	0	0	100	0	0	775000	0	500000	0.02978	0.0067
Venezuela	2,515,500	No data	No data	No data				2515500	0	2282500	0.08821	
Vietnam	4,795,500	4,620,500	0	0	100	0	0	175000	0	175000	0.04971	0.0479
Zambia	148,000	No data	No data	No data				148000	48000	100000	0.00829	
Zimbabwe	112,500	No data	No data	No data				112500	0	112500	0.00768	
TOTAL	**1,515,896,366**	**505,118,970**	**613,245,620**	**346,418,206**				**25,588,420**	**420,500**	**18,613,500**		

TABLE 19. **Use of Hemlibra in 2019**

(37 countries reported Hemlibra data)

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)
Argentina	4	15	15,000
Austria	3	2	
Cameroon	N/A	4	
Canada	37	6	172,385
Chile	2	0	
Colombia	46	46	46,120
Costa Rica	1	1	1,440
Cuba	6	1	5,490
Czech Republic	12	2	29,643
Dominican Republic	1	N/A	
Egypt	3	0	
Estonia	1	n/a	0
Finland	3	0	7,740
France	79	N/A	436,395
Georgia	N/A	N/A	4,995
Greece	3	2	22,890
Guatemala	2	N/A	
Hungary	5	N/A	
Ireland	7	7	33,945
Israel	22	45	
Jordan	2	0	0
Kenya	0	1	0
Kuwait	6	6	
Lithuania	4	0	5,280
Malaysia	6	0	0
Montenegro	1	N/A	1,920

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)
Panama	7	N/A	600
Poland	30	0	
Portugal	N/A	N/A	45,855
Saudi Arabia	29	21	72,800
Singapore	3	0	6,180
Slovak Republic	2	1	2,460
Slovenia	3	3	13,050
Sweden	13	0	
Thailand	5	5	
United Kingdom	96	133	500,365
United States	N/A	N/A	11,000,000

Annual Global Survey **2019**

A. National Hemophilia Organization

Organization name	
City	
Country	
Phone	
E-mail	
This form completed by:	First name Last name Email

Please Click Here **to validate Organization contact information**

The WFH would like to know how you collect the data you are providing for this survey. If you have a registry, we would like to know more about the registry. A registry is a regularly updated centralized list of identified people with hemophilia (PWH) or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment, and complications.

What is the source of the numbers provided for this survey?	**Check one** ☐ Hemophilia Society and/or NMO registry or database ☐ Hospital(s)/HTC(s) registry or database ☐ Health Ministry registry or database ☐ Other (please describe):
How often is your database updated?	☐ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
Who updates the database?	☐ Doctors update the database ☐ Patient organization updates the database ☐ Hospitals or clinics update the database ☐ Other (please describe):
Have all the identified patients in your country been included in this report? If not, please explain.	Yes ☐ No ☐ Please explain:

Please Click Here **to validate Data source**

Annual Global Survey **2019**

B. Identified Patients

The sum of *Male, Female,* and *Gender Unknown* should be equal to Total.

(Please DO NOT estimate or guess)	**Total**	**Male**	**Female**	**Gender unknown**	**No data**
1a. Total number of identified people with **hemophilia A**					☐
1b. Total number of identified people with **hemophilia B**					☐
1c. Total number of identified people with **hemophilia type unknown**					☐

2. Number of identified people with **von Willebrand disease (VWD)**					☐

3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders.					
Factor I deficiency					☐
Factor II deficiency					☐
Factor V deficiency					☐
Factor V+VIII deficiency					☐
Factor VII deficiency					☐
Factor X deficiency					☐
Factor XI deficiency					☐
Factor XIII deficiency					☐
Rare factor deficiency: type unknown					☐
Platelet disorders: Glanzmann thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

The sum of Total of the all other bleeding and platelets disorders should be equal to the number of OBD in question 3

A woman who has ≤40% of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

Please Click Here **to validate number of patients**

4. Number of people with Hemophilia and von Willebrand disease by age group

Age group	**Number with hemophilia A**	**Number with hemophilia B**	**Number with hemophilia type unknown**	**Number with VWD**
0 - 4 years old				
5 - 13 years old				
14 - 18 years old				
19 - 44 years old				
45 years or older				
Patients with age Unknown				
No age data	☐	☐	☐	☐

Annual Global Survey **2019**

The age distribution of Hemophilia A, B and unknown should be equal to the number of PWH in 1.
The age distribution of vWD should be equal to the number of vWD in question 2.

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
5. Do you collect age data in a format that does not match question 4? (If you do collect age data in another format, please send it to the WFH in a separate attachment.)		Yes ☐

Please Click Here **to validate Age section**

6. How are patients with rare bleeding disorders (deficiency in FI, FII, FV, FV+VIII, FVII, FX, FXI FXIII) classified?

Factor level measurements ☐	Clinical diagnosis ☐ (bleeding, family history)	Other ☐ (please describe):	No data ☐

How are patients with von Willebrand Disease classified?

Factor level measurements ☐	Severe bleeding symptoms ☐	Other ☐ (please describe):	No data ☐

7. Number of identified people with hemophilia by gender and severity

There are three levels of **severity** of hemophilia: **mild, moderate,** and **severe**. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

- A person (male or female) with >5-40 per cent of the normal amount of clotting factor has **mild** hemophilia.
- A person (male or female) with between 1-5 per cent of the normal amount of clotting factor has **moderate** hemophilia.
- A person (male or female) with less than 1 per cent of the normal amount of clotting factor has **severe** hemophilia.
- A woman who has ≤40% of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

Type of hemophilia	Mild (factor level above 5%)	Moderate (factor level 1% to 5%)	Severe (factor level below 1%)	Severity unknown	No Data
Hemophilia A male					☐
Hemophilia A female					☐
Hemophilia B male					☐
Hemophilia B female					☐

The sum of Hemophilia A Male mild, moderate, severe and unknown should be equal to number of Hemophilia A Male in question 1.
The sum of Hemophilia A Female mild, moderate, severe and unknown should be equal to number of Hemophilia A female in question 1.
The sum of Hemophilia B Male mild, moderate, severe and unknown should be equal to number of Hemophilia B Male in question 1.
The sum of Hemophilia B Female mild, moderate, severe and unknown should be equal to number of Hemophilia B female in question 1.

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

8. Number of severe VWD patients

Total number of severe (type 3) VWD patients	Number of VWD patients receiving replacement therapy	Number of VWD patients with severe bleeding symptoms	No Data
			☐

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

9. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors in 2019. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2019	No Data
Hemophilia A			☐
Hemophilia B			☐

Please Click Here **to validate classification, severity and inhibitors**

10 A. Availability and usage of products to treat hemophilia

Treatment product	Product is available	Number of patients treated with product indicated	No data
Plasma	☐		☐
Cryoprecipitate	☐		☐
Plasma-derived concentrate	☐		☐
Recombinant concentrate (excluding extended half-life)	☐		☐
Recombinant concentrate, extended half-life	☐		☐
DDAVP (Desmopressin)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

10 B. Availability and usage of non-factor products to treat hemophilia with inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Hemlibra (Emicizumab)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

10 C. Availability and usage of non-factor products to treat hemophilia without inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Hemlibra (Emicizumab)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

11. Availability and usage of products to treat VWD

Treatment product	Product is available	Number of patients treated with product indicated	No data
Plasma	☐		☐
Cryoprecipitate	☐		☐
Plasma-derived concentrate	☐		☐
DDAVP (Desmopressin)	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

Annual Global Survey **2019**

12. HIV infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people living with HIV			
New HIV infections in 2019			

13. Hepatitis C infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders
Total number of people infected with hepatitis C[1]			
Total number of people with currently active hepatitis C[2]			
New hepatitis C infections in 2019			

[1]Hepatitis C antibody positive at any time

[2]Still PCR positive: patients who have not cleared the virus spontaneously or after treatment

14. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2019)

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other inherited bleeding disorders
Bleeding			
HIV			
Liver disease			
Other causes			

Please Click Here **to validate products, HIV, HCV, and cause of death sections**

C. Hemophilia Care System in Your Country

We define as Hemophilia Treatment Centre (HTC) a medical centre providing any level of care (including basic diagnosis and treatment) for inherited bleeding disorders. Please provide the number of all such centres in your country. Please also indicate how many of those centers have **direct access, within the same structure,** to at least the following: hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory.

15. How many **hemophilia treatment centres** are there in total in your country?	
How many of the **hemophilia treatment centres** you have indicated above have **direct access, within the same structure,** to a hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory?	
Which percentage of the hemophilia patients in your country has access to a hemophilia treatment centre:	

Prophylaxis is regular, long-term treatment with clotting factor concentrates to prevent bleeds. Please indicate if the percentage provided is precise or an estimate.

16. What percentage of children (18 and under) **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What percentage of adults (over age 18), **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What is the most common dose (IU/kg) of factor administered and frequency?			

Immune tolerance induction (ITI) is the administration of FVIII or FIX concentrate in patients with inhibitors to eradicate the inhibitors. Please indicate the total # of patients with inhibitors who received ITI in your country in the last year, and the number of new patients who started ITI during the last year. Please indicate if these #s are precise or an estimate.

17. What is the total number of patients **with inhibitors** who received ITI during the last year?		Precise: ☐ Estimate: ☐	Not known ☐
Of this total, how many were new patients who **started** ITI treatment during the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Please Click Here **to validate Care section**

Annual Global Survey **2019**

D. The Cost and Use of Factor Concentrates

18 A. Annual usage of purchased factor concentrates (please do not include donated factor)	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2019 (excluding donated factor)?		☐		☐
Plasma derived: How many international units of **plasma-derived** concentrates were used in your country in 2019 (excluding donated factor)?		☐		☐
Recombinant, excluding extended half-life: How many international units of **recombinant** concentrates **(excluding extended half-life)** were used in your country in 2019 (excluding donated factor)?		☐		☐
Recombinant, extended half-life: How many international units of **recombinant** concentrates**, extended half-life** were used in your country in 2019 (excluding donated factor)?		☐		☐
If factor concentrates are purchased in your country but you are unable to report the quantities please check here:	☐		☐	

The Total of FVIII should be equal to sum of FVIII plasma-derived and FVIII recombinant
The Total of FIX should be equal to sum of FIX plasma-derived and FIX recombinant

18 B. Annual usage of donated factor concentrates	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
How many international units of **donated factor** concentrates (plasma-derived or recombinant) from all sources, including **Humanitarian Aid,** were used in your country in 2019?		☐		☐

18 C. Annual usage of purchased Hemlibra (Emicizumab)	**Amount (mg)**	**Not known**
How many milligrams (mg) of Hemlibra were purchased in your country in 2019? (Excluding donated product)		☐

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐

PLEASE NOTE: If a product used in your country is not listed, please add it at the bottom of the appropriate table.

Currency:	Tax included? No ☐ Yes ☐	Tax rate:

Please Click Here **to validate Factors section**

19. Factor VIII Concentrates used in 2019

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in the currency used to purchase the product. Please indicate if this price includes tax.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aafact	Sanquin	
☐	Advate rAHF PFM	Baxalta (now part of Shire)	
☐	Adynovate	Baxalta (now part of Shire)	
☐	Afstyla	CSL Behring	
☐	Aleviate	CSL Behring	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Bioclot A	Biofarma	
☐	Beriate P	CSL Behring	
☐	BIOSTATE	CSL Bioplasma	
☐	Conco-eight-HT	Benesis	
☐	Confact F	Kaketsuken	
☐	Cross Eight M	Japanese Red Cross	
☐	Elocta/Eloctate	Biogen Idec	
☐	Emoclot D.I.	Kedrion	
☐	FACTANE	LFB	
☐	Factor 8 Y	BioProducts Lab.	
☐	Faktor VIII SDH Intersero	Intersero	
☐	Fanhdi	Grifols	
☐	GreenEight	GreenCross	
☐	GreenGene	GreenCross	
☐	GreenMono	Greencross Corp	
☐	Haemate P (= Haemate HS)	CSL Behring	
☐	Haemoctin SDH	Biotest	
☐	Haemosolvate Factor VIII	National Bioproducts	
☐	Helixate NexGen = Helixate FS	CSL Behring	
☐	HEMO-8R	HEMOBRAS	
☐	Hemofil M AHF	Baxalta (Baxter Bioscience)	
☐	HEMORAAS SD plus H	Shanghai RAAS	
☐	HEMORAAS-HP, SD plus H	Shanghai RAAS	
☐	HEMORAAS-IP, SD plus H	Shanghai RAAS	
☐	Humate P	CSL Behring	
☐	Humafaktor 8	Human BioPlazma	
☐	Human Coagulation Factor VIII	Baltijas Terapeitiskais Serviss	
☐	Immunate	Baxalta (now part of Shire)	

☐	Koate DVI	Talecris	
☐	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
☐	Monoclate P	CSL Behring	
☐	Novoeight	NovoNordisk	
☐	Nuwiq	Octapharma	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Octavi SD	Octapharma	
☐	Octofactor	Generium/Pharmstandart	
☐	Optivate	Bio Products Laboratory	
☐	FVIII by Quimbiotec	Quimbiotec	
☐	Recombinate rAHF	Baxalta (now part of Shire)	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	TBSF purity factor, Koate DVI	Grifols	
☐	UNC Hemoderivados	Laboratorio de Hemoderivados de Universidad Nacional de Córdoba	
☐	Vihuma	Biotest	
☐	Voncento	CSL Behring	
☐	Western Province factor8 VIAHF	Western Province Blood transfusion Service	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

PLEASE NOTE: For “Other”, please provide the Brand Name and Manufacturer.

20. Factor IX Concentrates used in 2019

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aimafix	Kedrion	
☐	AlphaNine SD	Grifols	
☐	Alprolix	Biogen Idec	
☐	BeneFIX	Wyeth	
☐	Berinin-P = Berinin HS	CSL Behring	
☐	BETAFACT	LFB	
☐	Christmassin-M	Benesis	
☐	Clotnine	Hemarus	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Fixnove	Baxalta (now part of Shire)	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	

☐	Humafactor IX	Kedrion	
☐	Idelvion	CSL Behring	
☐	Immunine	Baxalta (now part of Shire)	
☐	MonoFIX-VF	CSL Bioplasma	
☐	Mononine	CSL Behring	
☐	Nanofix	Octapharma	
☐	Nanotiv	Octapharma	
☐	Nonafact	Sanquin	
☐	Novact M	Kaketsuken	
☐	Octafix	Octapharma	
☐	Octanine F	Octapharma	
☐	Replenine – VF	BioProducts Lab.	
☐	Rixubis	Baxalta (now part of Shire)	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

21. Prothrombin Complex Concentrates used in 2019

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Bebulin VH	Baxalta (now part of Shire)	
☐	Beriplex P/N	CSL Behring	
☐	Cofact	Sanquin	
☐	Facnyne	Greencross Corp	
☐	Haemosolvex Factor IX	National Bioproducts	
☐	HT DEFIX	SNBTS	
☐	Kanokad Confidex	LFB	
☐	KASKADIL	LFB	
☐	Octaplex	Octapharma	
☐	PPSB-HT	Nihon Pharmaceutical	
☐	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
☐	Profilnine SD	Grifols	
☐	Proplex – T	Baxalta (now part of Shire)	
☐	Prothrombinex PXT	CSL Bioplasma	
☐	Prothrombinex- VF	CSL Bioplasma	
☐	Prothromplex-T	Baxalta (now part of Shire)	
☐	Prothroraas	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

Annual Global Survey **2019**

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

22. Other Products used in 2019

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aryoseven	Aryogen	
☐	Byclot (1.5mg)	Kaketusken	
☐	Ceprotin	Baxalta (now part of Shire)	
☐	Clottafact Wilstart	LFB	
☐	Clottagen (fibrinogen)	LFB	
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
☐	FACTEUR VII	LFB	
☐	Factor VII	Baxalta (now part of Shire)	
☐	Factor VII	Bio Products	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxalta (now part of Shire)	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
☐	HEMOLEVEN (Factor XI)	LFB	
☐	Kovaltry	Bayer	
☐	NovoSeven (=Niastase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
☐	Riastap	CSL Behring	
☐	Tretten rXIII	NovoNordisk	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Other:		

PLEASE NOTE: For "Other", please provide the Brand Name and Manufacturer.

23. Non-factor products used in 2019

(Please check the box on the left if a product is used, and if known, fill out the number of patients and price per dose.)

Used	Brand Name	Manufacturer	Price per Dose
☐	Hemlibra (Emicizumab)	Roche	

GLOSSARY OF TERMS

Bernard-Soulier syndrome: A severe congenital bleeding disorder characterized by thrombocytopenia and large platelets, due to a defect in the platelet glycoprotein 1b/V/IX receptor.

Cryoprecipitate: A fraction of human blood prepared from fresh plasma. Cryoprecipitate is rich in factor VIII, von Willebrand factor, and fibrinogen (factor I). It does not contain factor IX.

Desmopressin (DDAVP): A synthetic hormone used to treat most mild cases of von Willebrand disease and mild hemophilia A. It is administered intravenously or by subcutaneous injection or by intranasal spray.

Extended half-life factor concentrate: A new generation of recombinant factor concentrates, which extend their half-life. Half-life is the time is takes for infused factor to lose half of its potency. Traditional factor VIII has a half-life of 8 to 12 hours; an extended factor VIII half-life is defined as a ratio greater than 1.3-fold, of the traditional half-life.

Factor concentrates: These are fractionated, freeze-dried preparations of individual clotting factors or groups of factors derived from donated blood.

Glanzmann's thrombasthenia: A severe congenital bleeding disorder in which the platelets lack glycoprotein IIb/IIIa, the blood platelet count is normal, but their function is very abnormal.

Hemophilia A: A condition resulting from factor VIII deficiency, also known as classical hemophilia.

Hemophilia B: A condition resulting from factor IX deficiency, also known as Christmas disease.

Hemophilia treatment centre: A specialized medical centre that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders.

HIV: Human immunodeficiency virus. The virus that causes AIDS.

Identified person: A living person known to have hemophilia, von Willebrand disease, or another bleeding disorder.

Inhibitors: A PWH has inhibitors when their body's immune system attacks the molecules in factor concentrate, rendering it ineffective.

International Unit (IU): A standardized measurement of the amount of factor VIII or IX contained in a vial. Usually marked on vials as 250 IU, 500 IU, 1000 IU or 2000 IU.

Mild hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity below normal but above 5% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%. The normal range of factor VIII or IX is 50 to 200%)

Moderate hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity between 1 to 5 % of normal activity in the bloodstream.

Plasma-derived products: Factor concentrates that contain factor VIII or IX that have been fractionated from human blood.

PWH: Person with hemophilia

Recombinant products: Factor concentrates that contain factor VIII or IX that have been artificially produced and are, therefore, not derived from human blood.

Registry: A database or record of identified people with hemophilia or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment and complications.

Severe hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity of less than 1 % in the bloodstream.

von Willebrand disease (VWD): An inherited bleeding disorder resulting from a defect or deficiency of von Willebrand factor.

REFERENCES

1. World Health Organization. 2019. Definition of regional groupings. https://www.who.int/healthinfo/global_burden_disease/definition_regions/en/. Accessed on March 10, 2019.
2. Soucie JM, Evatt B, Jackson D; Hemophilia Surveillance System Project Investigators. Occurrence of hemophilia in the United States. Am J Hematol. 1998;59:288-94.
3. Stonebraker JS, Bolton-Maggs PH, Soucie JM, et al. A study of variations in the reported haemophilia A prevalence around the world. Haemophilia. 2010;16:20-32.
4. Stonebraker JS, Bolton-Maggs PH, Soucie JM, et al. A study of variations in the reported haemophilia B prevalence around the world. Haemophilia. 2012;18:e91-4.
5. Calvez T, Chambost H, Claeyssens-Donadel S, et al; FranceCoag Network. Recombinant factor VIII products and inhibitor development in previously untreated boys with severe hemophilia A. Blood. 2014;124:3398-408.
6. Iorio A, Stonebraker JS, Brooker M, et al; Data and Demographics Committee of the World Federation of Hemophilia. Measuring the quality of haemophilia care across different settings: a set of performance indicators derived from demographics data. Haemophilia. 2017;23:e1-7.
7. Iorio A, Stonebraker JS, Chambost H, et al. Establishing the prevalence and prevalence at birth of hemophilia in males. Ann Intern Med. 2019;171:540-546.

WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA